National Institute for Health and Care Excellence

Draft for consultation

Stroke rehabilitation in adults (update)

[A] Evidence reviews for early supported discharge

NICE guideline GID-NG10175

Evidence reviews underpinning recommendations 1.1.8 to 1.1.11 in the NICE guideline

April 2023

Draft for Consultation

These evidence reviews were developed by the Guideline Development Team

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Contents

3 Experiences of early supported discharge (qualitative evidence)

3.1 Review question

In people after stroke what factors are associated with effective delivery of early supported discharge care?

3.1.1 Qualitative evidence

3.1.1.1 Included studies

Eighteen qualitative studies were included in the review;[5, 7, 8, 11, 12, 15, 20-22, 25, 28, 33, 34, 39, 40, 44, 47, 49] these are summarised in Table 1 below. Key findings from these studies are summarised in the clinical evidence summary below (**Table 2**). See also the study selection flow chart in Appendix C study evidence tables in Appendix E and excluded studies lists in Appendix L.

Interpretations and explanations from the original studies were synthesised to gain an insight into themes present across the body of evidence as a whole. The main concepts found in each individual study which were relevant to our review question were drawn together to inform understanding of overarching themes.

The majority of studies investigated the view of adults who have had a first or recurrent stroke, healthcare professionals or family members/carers. Limited information was identified discussing the views of adult social care workers as a part of the healthcare professionals discussing their experiences of early supported discharge. No relevant qualitative studies exploring the views of voluntary sector professionals were identified.

All studies included reported experiences of early supported discharge or home rehabilitation programs that were thought to be similar to early supported discharge. Evidence was mainly provided by people in Sweden or the United Kingdom, but also included people from Norway, Denmark, the Netherlands, Canada and Australia. The majority of studies used semi-structured interviews to gather information, while a small number used focus groups, qualitative survey data, Delphi approaches or a combination of multiple approaches. A narrative synthesis of the evidence can be found in 3.1.3 Summary of the qualitative evidence.

3.1.1.2 Excluded studies

See the excluded studies list in Appendix L .

3.1.2 Summary of studies included in the qualitative evidence

Table 1: Summary of the qualitative studies included in the evidence review

Study	Design	Population	Research aim	Comments
Chouliara 2014[5]	Cross-sectional qualitative study using semi-structured interviews.	**Healthcare professionals** (N=35) Practitioners, managers and commissioners from two Early Supported	To explore the perspectives of healthcare professionals and commissioners working with a stroke Early Supported Discharge service	Setting: Two early supported discharge services (one urban/city, one urban/town>semi-rural) in Nottinghamshire, United Kingdom

Study	Design	Population	Research aim	Comments
		Discharge services.	in relation to: (1) the factors that facilitate or impede the implementation of the service, and (2) the impact of the service.	
Cobley 2013[7]	Individual semi-structured interviews and thematic analysis.	**People after stroke** (N=27) Confirmed diagnosis of stroke assessed as requiring rehabilitation. **Family members/carers** (n=15) Carers of stroke survivors referred to an Early Supported Discharge service.	To investigate patients' and carers' experiences of Early Supported Discharge services and inform future Early Supported Discharge service development and provision.	Setting: Two stroke units in Nottinghamshire, United Kingdom
Collins 2016[8]	Individual semi-structured interviews and interpretative phenomenological analysis.	**People after stroke** (N=4) People who were recruited through the stroke early supported discharge service at a large teaching hospital.	To explore the experience of early supported discharge from the perspective of stroke survivors in Ireland.	Setting: Early supported discharge service linked to a large teaching hospital in the West of Ireland.
Ellis-Hill 2009[11]	Semi-structured interviews focussed on the person after stroke.	**People after stroke** (N=20) All people admitted to the stroke ward in the District General Hospital with a diagnosis of stroke. **Family members/carers** (N=13) The carers of stroke survivors.	To develop the understanding of what constitutes a 'good' and 'poor' experience in relation to the transition from hospital to home following a stroke.	Setting: People discharge from a range of different inpatient services with different packages of support in the United Kingdom. This study includes experiences of people who had early supported discharge and other types of discharge which has been considered in the relevance of outcomes.
Fisher 2013[12]	Delphi approach with 26 UK-based expert panellists.	**People after stroke** (N=1)	To establish the core components of evidence-based community stroke services by	Setting: 10 panellists from a hospital setting, 8 in the community, 8 at a university with a

Study	Design	Population	Research aim	Comments
		1 stroke survivor who participated in the panel. **Healthcare professionals** (N=25) 10 academics, 15 stroke service leads or commissioners.	using a modified Delphi consensus approach and building on a recently published Early Supported Discharge consensus document.	mixed geographic representation across the United Kingdom.
Hitch 2020[15]	A mixed methods case design including qualitative survey data and information from interviews and focus groups.	**Healthcare professionals** (N=23) Staff who referred people for early supported discharge and staff involved in the planning, implementation or delivery of early supported discharge.	To describe staff perceptions of the trial of an early supported discharge model of care for stroke survivors at a large metropolitan public hospital in Australia.	Setting: A public health organisation that delivered acute tertiary, subacute, specialist ambulatory and community-based services in a major Australia city.
Kjork 2019[20]	Explorative qualitative design with an inductive approach. Focus groups.	**Stroke survivors** (N=10) People who visited a clinical outpatient center. **Healthcare professionals** (N=8) Healthcare professionals working in the targeted outpatient clinics.	To explore the experiences, needs and preferences regarding follow-up perceived by people with stroke and healthcare professionals.	Setting: People from primary care or stroke specialised outpatient care at a university hospital in Sweden. The findings from this review may include people who partook in early supported discharge but it is unclear how many. This was considered when discussing the relevance of themes.
Kraut 2016[21]	Face-to-face, semi-structured interviews and subsequent thematic analysis.	**People after stroke** (N=10) A convenience sample of 10 inpatients. **Healthcare professionals** (N=19) Nine consultant doctors and 10 staff members who worked with the stroke survivors while they were in an	To explore the beliefs and attitudes of potential referrers and referrees regarding the possible utilisation of early supported discharge (ESR) prior to hospital discharge.	Setting: Inpatients who were referred to the Rehabilitation in the Home service in Australia.

Study	Design	Population	Research aim	Comments
		acute care hospital.		
Lou 2017[22]	Qualitative interview study with thematic analysis.	**People after stroke** (N=22) Stroke patients who were recruited by three of the regional stroke teams. **Family members/carers** (N=22) Partners of the same people after stroke.	To investigate how mild stroke patients' and their partners' experience and manage everyday life in a context of early supported discharge.	Setting: Three regional stroke team services in Denmark.
Moule 2011[25]	Initial qualitative interview followed by additional interviewing and then thematic analysis.	**Healthcare professionals** (N=10) Members of the early supported discharge team or key external stakeholders from different disciplines.	How did the early supported discharge team members and external stakeholders experience the service implementation process?	Setting: Interviews were conducted at the team members' place of work, at the University in one case, in the respondents house in one case in the United Kingdom.
Nordin 2015[28]	Interview followed by qualitative content analysis.	**People after stroke** (N=10) Stroke survivors with confirmed stroke according to the World Health Organisation criteria.	To describe patients' expectations of coming home very early after stroke with support and rehabilitation at home.	Setting: Interview study nested within a randomised controlled trial (GOTVED) in Sweden.
Ringsberg 2003[33]	Phenomenographic approach with semi-structured interviews.	**People after stroke** (N=15) People selected from a special stroke unit for rehabilitation in their homes by a special rehabilitation team. **Family members/carers** (N=15) Family members/carers partnered with the stroke survivors.	To capture stroke patients' and their relatives' conceptions of home rehabilitation with special focus on their participation in the decision about home rehabilitation, their participation in the rehabilitation and their experiences of the rehabilitation team.	Setting: People from a special stroke unit for rehabilitation who were discharged to home for continuing rehabilitation in Sweden.
Rochette 2021[34]	Cross-sectional study using a mixed methods approach with	**Family members/carers** (N=90)	To describe their perception of the quality of the services they	Setting: Early supported discharge, outpatient and inpatient

Study	Design	Population	Research aim	Comments
	2qualitative content by the way of two open-ended questions and free-space for comments to quantitative questions.	People who had relatives who accessed early supported discharge (n=29), in-patient rehabilitation (n=41) and outpatient rehabilitation (n=20).	received in the context of early supported discharge, in- and out-patient rehabilitation services.	rehabilitation services in Canada. Includes experiences from people who did not access early supported discharge services. Themes were extracted from those who only received early supported discharge.
Taule 2014[39]	Qualitative interpretative interview design relying on interpretative description from individual interviews.	**People after stroke** (N=8) People who participated in a larger randomised controlled trial designed to investigate early supported discharge.	To explore experiences of mild-stroke survivors in the context of early supported discharge.	Setting: People who took part in an early supported discharge trial in Norway.
Taule 2015[40]	Qualitative interpretative interview design relying on interpretative description from individual interviews.	**People after stroke** (N=8) People in the home rehabilitation group of a randomised controlled trial.	The aim of this study was to explore mild-to-moderate stroke survivors' experiences with home rehabilitation after early supported discharge from hospital.	Setting: People who participated in an early supported discharge trial in Norway.
van der Veen 2019[44]	Focus groups utilising a naturalistic study design based upon a constructionist epistemology (with telephone interviews for those who could not attend) and content analysis.	**Healthcare professionals** (N=15) Professionals from a range of backgrounds including physicians, allied health professionals and managers.	To explore professionals' perspectives on the provision of Home-Based Stroke Rehabilitation (HBSR) in the Netherlands and on the barriers and facilitators influencing the implementation of HBSR in daily practice.	Setting: Professionals from a range of work settings (inpatient, outpatient, primary care). Mixture of focus groups and telephone interviews in the Netherlands. This study does not directly discuss early supported discharge, instead discussing home based stroke rehabilitation. This was considered when interpreting relevance.
von Koch 2000[47]	Semi-structured interviews followed by thematic analysis.	**Healthcare professionals** (N=6) Two occupational therapists, two physical	To describe the content of a programme involving early hospital discharge and continued	Setting: Interviews at a university hospital with professionals working in the home rehabilitation program in Sweden.

Study	Design	Population	Research aim	Comments
		therapists and one speech and language therapist (who was later replaced with another speech and language professional due to changed positions).	rehabilitation at home after stroke.	
Wottrich 2007[49]	Interviews analysed using a phenomenological approach.	**Healthcare professionals** (N=13) Multiprofessional outreach team (physiotherapists, occupational therapists, speech and language therapists and a social worker).	To identify the meaning of rehabilitation in the home environment after stroke from the perspective of members of a multiprofessional team.	Setting: People working in an outreach team attached to a geriatric hospital in Sweden.

See Appendix E for full evidence tables.

3.1.3 Summary of the qualitative evidence

Table 2: Qualitative review findings

Main findings	Statement of finding
1) Person-centred care: the underpinning principle of early supported discharge success[5, 8, 15, 22, 34, 40, 44, 47, 49]	Stroke survivors, family members and carers and healthcare professionals all agreed that the main benefit of early supported discharge was the ability to provide person-centred care in a way that was possible in a person's home and not possible in a hospital.
2) Clear, transparent referral pathways	
a) Clear and fair eligibility criteria[5, 12, 21, 22, 33]	Healthcare professionals all appreciated the presence of clear and fair eligibility criteria that are sufficiently flexible to allow the correct people to access early supported discharge. Stroke survivors and family members and carers were generally unaware of the criteria for early supported discharge.
b) Lack of clarity regarding the referral decision making process[5, 12, 25]	Healthcare professionals raised that there can be a lack of clarity regarding the referral decision making process for early supported discharge, and how the different services after discharge interact.
c) Delays from starting care due to paperwork/bureaucracy[5, 20, 40, 49]	Some stroke survivors and family members and carers believed that their care was delayed due to the process of transferring care between services. However, some participants had a different experience and found that the care they needed was less likely to be delayed than if they had not received early supported discharge.
3) Managing beliefs about early supported discharge: stroke survivor, family member and healthcare professionals	

Main findings	Statement of finding
a) Stroke survivor/family member expectation of what will happen in early supported discharge[7, 8, 12, 22, 28, 33, 34, 40]	Stroke survivors and family members were unclear about what to expect from early supported discharge and felt like they had inadequate information provided to understand this ahead of time.
b) Stroke survivor/family member/healthcare professional expectation of challenge: physical, psychological and social[8, 28, 44]	Stroke survivors, family members and healthcare professionals expected that there would be challenges when the person went home.
c) Stroke survivor/family member expectation to return to 'normal' after early supported discharge[5, 8, 11, 15, 20, 22, 28, 33, 39, 40, 44, 49]	Initially after stroke, motivation to return to how their life was before the stroke was high. This understanding was moderated by the amount of recovery the person was experiencing. This idea was often at the forefront of stroke survivors' thoughts, but behind this was anxiety at whether this was possible or not which was coupled with frustration when the evidence indicated they were not returning to the normality that they wished for.
d) Stroke survivor/family member/healthcare professional expectation that the family member will help[5, 11, 21, 33]	Where family members were involved in the life of the stroke survivor, there appeared to be an assumption by everyone that they would be supporting the stroke survivor once they got home.
e) Stroke survivor/family member expectation that they will work with professionals experienced in stroke[12, 20, 28, 40, 44]	Stroke survivors and family members expected that the healthcare professionals working with them would have a significant amount of experience with stroke and would be able to provide them with information and guide their care effectively.
f) Beliefs about intensity of therapy[5, 7, 12, 15, 21, 33, 40, 44, 47]	There was inconsistency in people's beliefs and experiences regarding the intensity of therapy that would be provided during early supported discharge with the majority believing it increases intensity while others believed it reduced this.
g) Beliefs about the cost of early supported discharge[12, 15, 25]	The thoughts on the cost of early supported discharge was a moderator for whether people consider the service appropriate to use or not.
4) The stroke survivor's experiences that need consideration	
a) Loss of independence – sometimes needing support[28, 33, 39]	Discharge after stroke was often associated with a realisation of a loss of independence and requiring support from family members or friends and healthcare professionals that they would not have required previously. This was often associated with feelings of loss.
b) Changing relationships: with their partners[7, 11, 20, 22, 33, 40], friends[11, 33, 39, 40] and children/grandchildren[11, 21, 22, 28, 39, 40]	Stroke survivors and people they are in relationships with (from the views explored in these studies, either married or long term partner) can experience significant changes in their roles after the stroke, with the partner becoming a caregiver and the stroke survivor becoming a patient who needs support. The stroke survivor's relationship with their friends often changes. This is due to a mixture of factors including the stroke survivor's ability to interact with the outside world due to a mixture of less physical and emotional access, reduced ability to withstand conflicts and reduced ability to manage familiar activities with others.

Main findings	Statement of finding
	For parents and grandparents, they found that their relationships with their children and grandchildren changed after their stroke. For some their children and grandchildren may become carers to support them and so undergo a similar transition to partners in this regard and gain the challenges associated with this. For parents and grandparents who are still caring for their children, the challenges of adapting to their life after stroke and providing the care required were significant.
c) The future – What is life going to look like? Will I have another stroke? [7, 8, 11, 18, 20, 22, 33, 39, 40]	Stroke survivors were commonly concerned about what the future would be like after their stroke including future plans and the possibility of having another stroke in the future.
5) Involving and supporting family	
a) From family member to carer[21, 22, 28, 33, 44]	Family members who are involved in the care of a stroke survivor can experience a large change in their life where they transition from being a family member to helping to provide care and support to their family member who has had a stroke.
b) Not involved in decision making[21, 33, 34, 44]	Even though family members were seen to be important in deciding whether someone could use the early supported discharge services, family members often found that they were not included in the decision making process.
c) Lack of training for carers[7, 33, 47]	Family members who were supporting with care also reported that they did not receive enough training and information for the role they would need to place. Family members may need to provide support with problem-solving that they may not know how to do in a way that manages the complex interaction of encouraging the person's autonomy while also providing the support they need.
d) Limited support for carers[7, 15, 22, 33, 34]	In addition, family members agreed that there was limited support available for carers. Carers were often left exhausted and physically strained, having to undertake tasks that the other person may have done initially on top of their usual responsibilities.
6) Making home (and life beyond) safe and enriching for rehabilitation	
a) Wanting to return home as soon as possible balanced against feeling safe in hospital[7, 8, 15, 21, 22, 25, 28, 33, 47, 49]	The people in the studies reported a mixture of feelings regarding returning home that varied from wanting to return home as soon as possible to feeling safe in hospital and so not wanting to return home too early.
b) Home as a place of familiarity[8, 11, 21, 28, 40, 49]	People after stroke referred to home as a place of familiarity where, once they returned, they would start to feel more like themselves again. Returning home would allow them to have access to their own things and see the people they wanted to see. However, there was a thought from some that while being home in a familiar situation was initially exclusively positive, as time passed it became more of a hindrance.
c) Home as a new training ground/workplace[22, 28, 33, 44, 49]	Returning home for early supported discharge created a new place full of challenges that required solutions. This meant that people sometimes felt like home was a new training ground or workplace.

Main findings	Statement of finding
d) Suitability of home/equipment[7, 21, 28, 33, 49]	As early supported discharge is prepared for, discussions need to be had on the suitability of the home and whether additional equipment is required. While home can provide additional challenges that may help rehabilitation, it was noted that homes may not always be suitable and may be a problem that hinders rehabilitation instead.
e) Returning to work[18, 39]	The experiences of returning to work varied from seeing a lot of benefit from returning to normality but also that, due to the changing pace of life that is seen with people during early supported discharge anyway, that this can lead them feeling like they may be less able to do their job.
7) The need for psychological support	
a) Motivation[8, 18, 22, 28, 39, 40, 47]	Motivation and how to maintain this was commonly discussed. A common experience discussed was an initial hope filled period where people were seeing significant improvements with rehabilitation that motivated them to do more. However, if these improvements are not as apparent, start to slow down or are not to the amount that the person would want in their journey to return to 'normal', then this will reduce motivation.
b) Control[8, 18, 22, 28, 39, 40, 49]	After a stroke, the experience of control starts to change. Early supported discharge is an opportunity to restore control by being in their home and their own environment. However, recovering from a stroke is associated with a wish to gain more control of their body and their life. Some parts of their life after a stroke are not controllable and can lead to more distress.
c) Loss[33, 39]	As life has changed significantly there is a loss associated with what has changed. This is coupled with changes in emotionality that can come after a stroke, which becomes more apparent as time passes.
d) Mild stroke and feelings associated with invisible disability[22, 39]	People after mild stroke, who may be eligible for early supported discharge, may experience feelings associated with having an invisible disability, where their experience of life has changed a lot and makes life more difficult in ways that other people may not notice or realise.
e) Adapting to life being different[8, 11, 18, 21, 22, 28, 33, 39, 49]	After a stroke people have to adapt to their new experience of life, but how they do this varies between different people. This adaptation includes physical adaptations to the home as well as changes in their behaviour.
f) The need for psychological support[5, 7, 39, 40, 47, 49]	With all of these factors taken into account, there is a need expressed by some stroke survivors for psychological support. Early supported discharge provided to key opportunity for addressing the emotional and cognitive challenges that stroke survivors experience, that may become more apparent when they return home.
8) Effective multidisciplinary teamwork	
a) Collaborative work between different professions and the stroke survivor[5, 25, 40, 44, 47, 49]	The early supported discharge team worked at its best when there was a collaboration between different

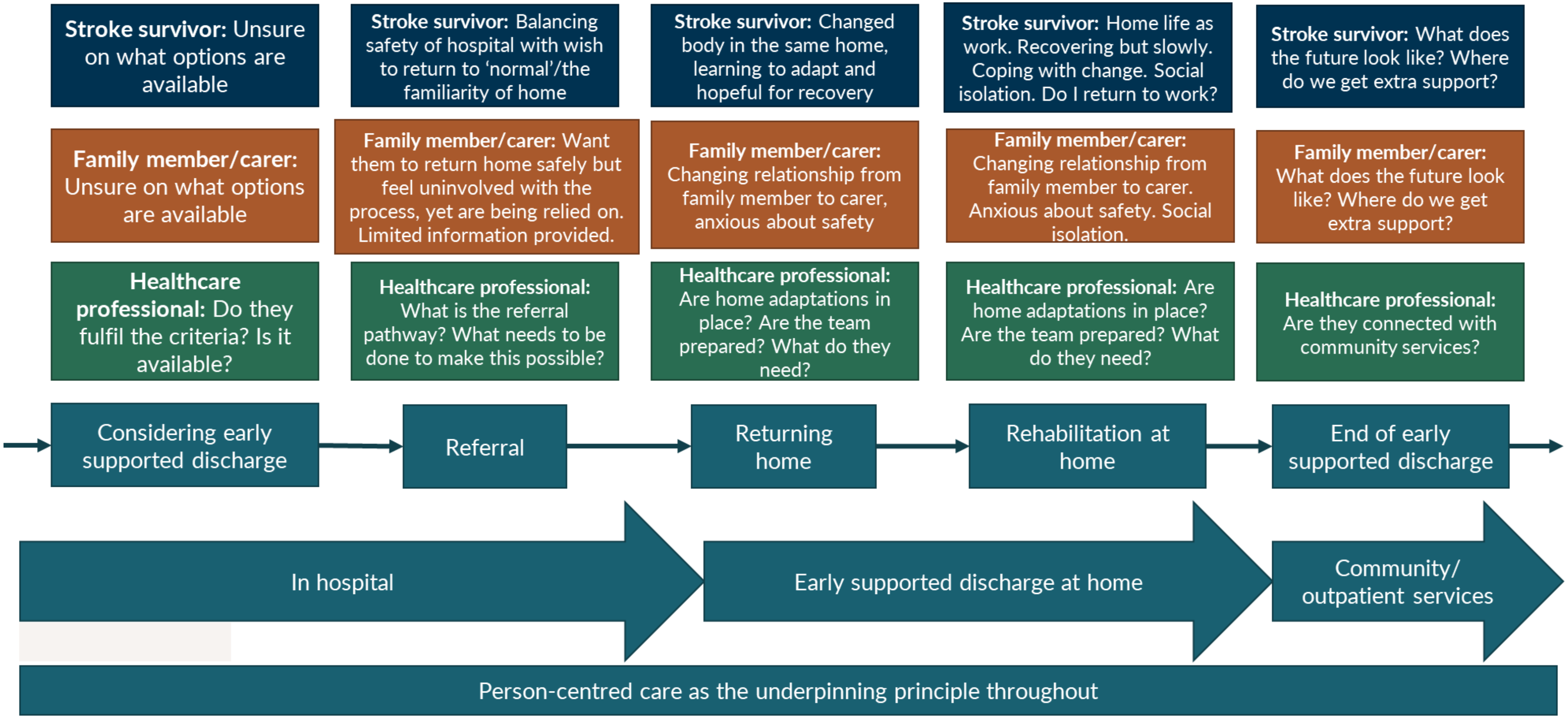
Main findings	Statement of finding
	professions, the stroke survivor and others involved in their care.
b) The need for early supported discharge coordination[15, 22, 34, 44]	One part noted to be important to the success of early supported discharge was to have a staff member who was responsible for coordinating the care received by the person.
c) Who is in the team? Staff requirements[5, 12, 25]	The staff members who make up the early supported discharge team were discussed. While some members were taken as obviously included (for example: allied health professionals, physicians) a few members were emphasised. The first were rehabilitation assistants, the second were social care professionals.
d) Relationship between the stroke survivor and early supported discharge professionals: encouraging their journey[8, 18, 22, 40, 47, 49]	The relationship between the stroke survivor and the healthcare professionals and the role that healthcare professionals play in their rehabilitation was raised. Healthcare professionals were initially ‘strangers’ who stroke survivors were forced to be together to restore them to their pre-stroke self who they may not want to come into their home. However, as time passes and they journey together the stroke survivor may find the healthcare professionals progressing towards friendship. Healthcare professionals saw their role to encourage the person to identify the challenges in their life and to work together while encouraging the person to find their problem-solving skills.
e) Trust[21, 33, 40, 47]	When being delivered effectively, stroke survivors and family members reflected that they trusted healthcare professionals to be experts and provide knowledge that they otherwise would not have.
f) Access to professionals when you need them[11, 28, 34]	Stroke survivors and family members found that during early supported discharge they could have access to support from healthcare professionals whenever they need it.
9) Collaboration between other services	
a) Fragmented and inconsistent stroke care pathway[5, 12, 25, 40, 44]	Healthcare professionals and stroke survivors reported that the stroke care pathway and where early supported discharge sat in that was confusing, in particular where it sits among other community services.
b) Methods for increasing collaboration[5]	Healthcare professionals discussed methods that could be used to increase collaboration between different services. This included allowing staff to experience the approach by introducing a rotational element between people who could be involved with the team and participation in meetings and common training events.
10) Providing care for as long as required	
a) Providing therapy for as long as it is needed[5, 7, 12, 15, 33, 34, 40, 47, 49]	A discussion between participants took place as to how long therapy should be provided. Noting the person-centred nature of early supported discharge, some healthcare professionals believed that supported should not be provided for an arbitrary amount of time and instead for as long as the person needed it. However, early supported discharge services were often provided for a set amount of time, with the

Main findings	Statement of finding
	understanding that some people may need less or more support.
b) Early supported discharge bridging the gap between inpatient and community services[5, 7, 12, 25, 28, 49]	Early supported discharge is an important opportunity to try and support the transition from inpatient to community services, which can be a problem experienced by stroke survivors whether they are taking part in early supported discharge or not.

See Appendix J for full GRADE-CERQual tables.

3.1.3.1 Diagrammatic summary of key findings

Figure 1: A flow diagram indicating the potential thoughts of different stakeholders during the early supported discharge process



Considering early supported discharge	Referral	Returning home	Rehabilitation at home	End of early supported discharge
Stroke survivor: Unsure on what options are available	**Stroke survivor:** Balancing safety of hospital with wish to return to ‘normal’/the familiarity of home	**Stroke survivor:** Changed body in the same home, learning to adapt and hopeful for recovery	**Stroke survivor:** Home life as work. Recovering but slowly. Coping with change. Social isolation. Do I return to work?	**Stroke survivor:** What does the future look like? Where do we get extra support?
Family member/carer: Unsure on what options are available	**Family member/carer:** Want them to return home safely but feel uninvolved with the process, yet are being relied on. Limited information provided.	**Family member/carer:** Changing relationship from family member to carer, anxious about safety	**Family member/carer:** Changing relationship from family member to carer. Anxious about safety. Social isolation.	**Family member/carer:** What does the future look like? Where do we get extra support?
Healthcare professional: Do they fulfil the criteria? Is it available?	**Healthcare professional:** What is the referral pathway? What needs to be done to make this possible?	**Healthcare professional:** Are home adaptations in place? Are the team prepared? What do they need?	**Healthcare professional:** Are home adaptations in place? Are the team prepared? What do they need?	**Healthcare professional:** Are they connected with community services?

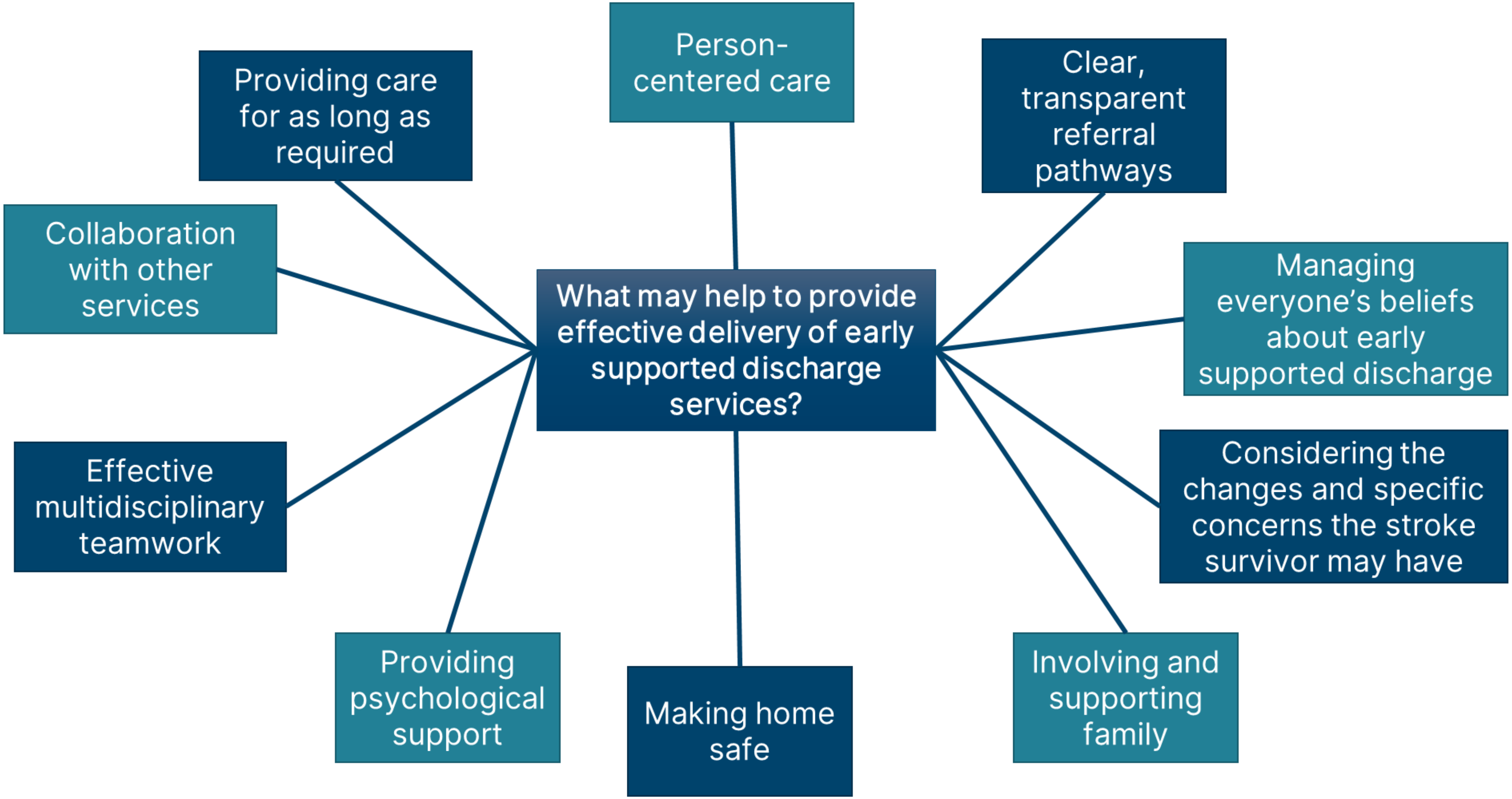
In hospital

Early supported discharge at home

Community/ outpatient services

Person-centred care as the underpinning principle throughout

Figure 2: A diagrammatic representation of the main themes identified in the review



3.1.3.2 Narrative summary of review findings

Review finding 1: Person-centred care: the underpinning principle of early supported discharge success[5, 8, 15, 22, 34, 40, 44, 47, 49]

Stroke survivors, family members and carers and healthcare professionals all agreed that the main benefit of early supported discharge was the ability to provide person-centred care in a way that was possible in a person's home and not possible in a hospital ('At home, with their coming here, I felt I was an individual, it was especially for me ... that kind of feeling it wasn't like I was a number in the hospital, I was somebody, I was at home and somebody was coming to help me.'[8]). The nature of this allows for the service to be more holistic in addressing the needs of the person, including their physical, psychological and social needs ('It is less about a body in a bed that needs a bit of fixing; to me, it feels more of a holistic service; just being in peoples' houses, seeing what problems they actually have and adapting the service around that' ESD Team Member, 30[5]). This allowed for more meaningful goal setting and for individually tailored advice. Where early supported discharge was perceived as more successful was when the stroke survivor worked with the healthcare professional to identify problems and find solutions together ("In the hospital, this big institution where you are an authority in a white coat, the patient submits himself to you and wants you to help him and make him well. But at home I think it's more like you discuss the patient's problems and co-operate with him to find solutions."[47]). When this is achieved this empowers the stroke survivor to better find solutions in the future improving their ability to cope with life after their stroke. Stroke survivors reflected that when early supported discharge was less successful was when it was not person centred and provided care that, while useful, did not address their needs (A man in his 80s with stroke-related memory-difficulties told how he 'suffered' when his problem emerged in conversations, especially with his children (participant 3). Speaking about the treatment he was offered, he told of aids and hand exercises. Findings like this illuminate that treatment was not sufficiently guided by the patients' needs[40]).

Explanation of quality assessment: minor methodological limitations in the contributing studies (due to a lack of clarity in whether the relationship between researcher and participants had been considered and whether data analysis was sufficiently rigorous in some studies); no or very minor concerns about the coherence of the finding with nothing to lower our confidence; minor concerns about relevance due to the majority of contributing studies representing the views from countries that were not in the United Kingdom (such as Sweden, Denmark, Australia and Canada) and so may have had a different cultural experience of healthcare and for some studies discussing home rehabilitation rather than specifically early supported discharge, which were both deemed unlikely to have a large effect on the finding; no or very minor concerns about adequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate confidence in this finding due to the concerns regarding the methodological concerns and partial applicability of this finding.

Review finding 2: Clear, transparent referral pathways

This theme included 3 subthemes, including: Clear and fair eligibility criteria; Lack of clarity regarding the referral decision making process and Delays from starting care due to paperwork/bureaucracy.

Review finding 2a: Clear and fair eligibility criteria[5, 12, 21, 22, 33]

Healthcare professionals all appreciated the presence of clear and fair eligibility criteria that are sufficiently flexible to allow the correct people to access early supported discharge ('I think the criteria are good because they are not too defined or too loose; I think there are very few inappropriate people that come through' Stroke Physician, 1[5]). Healthcare professionals agreed that people with milder stroke would be eligible for early supported discharge while people with more severe stroke require rehabilitation in hospital and should only be transferred into the community when they can be supported at their place of residence[12]. To describe the needs of a person who they would consider able to return home, a healthcare professional said 'Well, she'd virtually have to be independent to walk because we won't be there at her beck and call, so she'd have to be able to get up, get out of the bed, go to the toilet and just do the basic things ... by herself.’. Participants in one study agreed that the ability to set goals ahead of rehabilitation should not be a barrier as "Goals may not be particularly clear initially due to psychological, communication or cognitive factors."[12] while others in the same study felt that this was important to avoid advocating “unlimited and unfettered access” and aid service planning[12].

Stroke survivors and family members and carers were generally unaware of the criteria for early supported discharge (see review finding 3c – the one about inadequate information), however they reflected that they trusted that healthcare professionals would only be referring them if they believed, in their expert opinion, that it was the right choice (‘The relatives also expressed that it was positive that the patient was offered home rehabilitation. They trusted the staff's assessments that both they and the patient would manage it. 'He wanted to go home, you know, and I suppose I thought that it was nice that he was allowed to come home, that it's easier.' (50). 'O well, I believe in those people'. (52).’[33]. Stroke survivors and family members agreed that it would not be possible if the person was not ambulant before going home, but the definition of what this meant varied ‘from a few steps with minimal assistance’ to ‘complete independence’[21] ('I think I need to be able to stand for longer ... walk a bit better ... by myself ... I need my left hand working ... because right now, it's not doing anything. - Patient 6'.[21]. The consensus was that people needed to at least able to ambulate and achieve activities of daily living with minimal assistance. These criteria may be flexible dependent on the availability of extra support from family members and carers (see review finding 3e).

Explanation of quality assessment: moderate methodological limitations (due to a combination of problems with the recruitment process in one study, a lack of clarity in whether the relationship between researcher and participants had been considered, a lack of information about whether ethical concerns were addressed and whether data analysis was sufficiently rigorous in one study); minor concerns about the coherence of the finding due to disagreement between professionals regarding the use of ability to make meaningful goals as a criteria; minor concerns about relevance due to the majority of contributing studies representing the views from countries that were not in the United Kingdom (such as Sweden, Denmark and Australia) and so may have had a different cultural experience of healthcare; no or very minor concerns about inadequacy as the evidence is sufficiently deep. There was a judgement of low confidence in this finding due to the concerns regarding the methodological concerns, coherence and partial applicability of this finding.

Review finding 2b: Lack of clarity regarding the referral decision making process[5, 12, 25]

Healthcare professionals raised that there can be a lack of clarity regarding the referral decision making process for early supported discharge, and how the different services after discharge interact (see review finding 9a). Some healthcare professionals did not understand what was involved in early supported discharge and so felt they were not able to appropriately advocate for their patient ('Just getting a bit more understanding of what the content is so that we can decide the Early Supported Discharge is in the best interests of the patient' Acute Stroke Unit Staff, 8[5]). The absence of knowledge meant that the team was not able to effectively inform stroke survivors and family members leading to further confusion (see review finding 3c). There was debate about when the best time to consider early supported discharge was, with some believing that it should be considered ‘the minute patients arrived in the acute unit’ while others argued that the first two weeks after stroke was too early for such decisions as ‘a lot of recovery will be happening while patients are still on the acute (unit)’[5]. Professionals disagreed on how to distinguish between early supported discharge services and the community stroke rehabilitation team, with some believing there was a clear delineation between the two based on the intensity that could be provided by the early supported discharge team compared to community stroke rehabilitation teams, while others believed that a more flexible approach was more important to allow for a better integration of the care pathway)[12]. Challenges present at the referral process would also be present at the end of the early supported discharge service when referring to community stroke teams and then again when returning responsibility to primary care physicians (see review finding 3b and 10b).

Explanation of quality assessment: moderate methodological limitations (due to a combination of problems with the recruitment process in one study, a lack of clarity in whether the relationship between researcher and participants had been considered and a lack of information about whether ethical concerns were addressed); minor concerns about the coherence of the findings due to debate on when early supported discharge should be considered and the differences in knowledge between different types of healthcare professionals; no or very minor concerns regarding relevance; minor concerns about inadequacy as the evidence was gathered from three studies and there appeared to be gaps in knowledge that could provide additional information discussing this subtheme. There was a judgement of low confidence in this finding due to concerns regarding the methodological concerns, coherence and adequacy of the finding.

Review finding 2c: Delays from starting care due to paperwork/bureaucracy[5, 20, 40, 49]

Some stroke survivors and family members and carers believed that their care was delayed due to the process of transferring care between services. This was explained by one person: "They told me I had to wait because of some paperwork that had to be done. They put me aside for several weeks before I got started [with my follow-up treatment], while I felt it was very urgent for me. I lost some [valuable] time, and when I got started I had lost the glow, and they lost a little glow too, and then we were, not enemies, but I ... [sentence not completed]. (Participant 7)".[40]. Healthcare professionals identified that this may have been delays in early supported discharge programs linked to challenges organising care packages ('Patients were bottlenecking up at the other end because their care packages wouldn't be ready; at eight weeks we'd still got these patients'. Service Management, 18[5]) that were less likely to be present when a social worker was a part of the early supported discharge team[5] (see review finding 8c – the one about the need for social worker in the team). Another study discussed how the provision of home adaptations took longer than needed which lead to a loss of confidence and routines[49]. There was an expectation that adaptations would be put in place before starting or early in the early supported discharge process (see review finding 5d).

However, some participants had a different experience and found that the care they needed was less likely to be delayed than if they had not received early supported discharge (‘People who received early supported discharge (ESR) automatically received follow-up. In contrast, people who did not receive early supported discharge experienced worries and a substantial wait for the ordinary follow-up visit.’[20]). People could get the approach that they required, rather than the approach that may be experienced in primary care where they get asked about medicines rather than the bigger questions that they need specialist help to answer[20].

Explanation of quality assessment: moderate methodological limitations (due to a combination of problems with a lack of clarity in whether the relationship between researcher and participants had been considered and a lack of information about whether ethical concerns were addressed); minor concerns about the coherence of the findings due to variations in whether delays were experienced or not; minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Norway and Australia) and so may have had a different cultural experience of healthcare and for some studies discussing home rehabilitation rather than specifically early supported discharge, which were both deemed unlikely to have a large effect on the finding; no or very minor concerns about adequacy as the evidence is sufficiently deep. There was a judgement of low confidence in this finding due to the concerns regarding the methodological concerns, coherence and partial applicability of this finding.

Review finding 3: Managing beliefs about early supported discharge: stroke survivor, family member and healthcare professionals

This theme included 7 subthemes, including: Stroke survivor/family member expectation of what will happen in early supported discharge; Stroke survivor/family member/healthcare professional expectation of challenge: physical, psychological and social; Stroke survivor/family member expectation to return to ‘normal’ after early supported discharge; Stroke survivor/family member/healthcare professional expectation that the family member will help; Stroke survivor/family member expectation that they will work with professionals experienced in stroke; Beliefs about intensity of therapy and Beliefs about the cost of early supported discharge.

Review finding 3a: Stroke survivor/family member expectation of what will happen in early supported discharge[7, 8, 12, 22, 28, 33, 34, 40]

Stroke survivors and family members were unclear about what to expect from early supported discharge and felt like they had inadequate information provided to understand this ahead of time. The expectations they did have were that the team would check their home environment and how they managed there ("The first few days after I got home, they should be able to work out what I can't manage to do, what I'm going to need help with". - Participant 4[28]), they would receive support to manage at home with their daily activities ("...we decided that on the first day that I was going to cook and she was going to be with me. How to get it to work and the like. // Make something myself, lunch or something. I'm going to try to do it myself, but they would be, she would be with me." - Participant 7[28]) and lead to them mastering their environment. They would also support them to return to their former abilities and help in their journey to return to their previous life (see Review Finding 3a).

However, the majority of studies reflected the stroke survivors and family members were provided with insufficient information to understand what will happen ('To be quite honest with you, I don't know how to describe it...they [staff in hospital] told me I'd get home; they told me about this ... then just in a couple of days I got home here.' 'I'm not sure exactly ... the physio came out and gave me exercises ... and the OT helped me with the thing in the bathroom to get into the bath, and the little trolley for wheeling meals ... so that was the input from the early supported discharge'[8]). There was a feeling that they were not completely involved in the decision making process ('No, they came with that paper and said sign here. I think you should take part in the training.' (8) 'No I didn't really know what it was all about. But they thought that now I should do my exercises at home.' (8)[33]).

Stroke survivors and family members explained that what they would like more information about what early supported discharge was and in particular people wanted information, practical advice and wanted the situation to be normalised ('Just knowing that what you're going through is normal...for your situation. That means the world. Because then you are not taken by surprise. You know what's coming and that it is normal and expected'. Beate (patient)[22]).

Explanation of the quality assessment: moderate methodological limitations (due to a combination of problems including a lack of clarity in whether the relationship between researcher and participants had been considered, two studies where the rigor of the data analysis was unclear, one study where it was unclear if the recruitment strategy was appropriate and one study where it was unclear if ethical issues have been considered); no or very minor concerns about the coherence of the findings were identified; minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Denmark, Norway and Canada) and so may have had a different cultural experience of healthcare; minor concerns about adequacy as the evidence as the expectations of stroke survivors and family members are only explained in one study, with the majority of studies supporting the lack of information instead. There was a judgement of low confidence in this finding due to the concerns regarding the methodological concerns, partial relevance and adequacy of this finding.

Review finding 3b: Stroke survivor/family member/healthcare professional expectation of challenge: physical, psychological and social[8, 28, 44]

Stroke survivors, family members and healthcare professionals expected that there would be challenges when the person went home. These problems included physical, psychological and social challenges. People felt safe in the hospital and home would have the potential to be in some ways less safe('You feel very safe, very secure in the hospital'[8]). Challenges with their emotions may reduce their ability to participate in activities even more ("It's just that, going out of your apartment, now I don't want to do that. I mean if I fell over there, maybe no-one would notice and realize 'she's unwell' //, or ring for an ambulance, so I'm a bit scared of that ..." - Participant 3[28]). However, as information about what to expect from early supported discharge was limited (see Review Finding 3c) the awareness of the degree to which these challenges may affect the stroke survivor may be different. In comparison, healthcare professionals were aware of the challenges that the person may face ("Every activity can be a challenge. Someone <client> has a lot to do. They find themselves within a skills lab, for 16 hours a day!" - Manager in allied healthcare, primary care[44]).

Explanation of the quality assessment: minor methodological limitations (due to a lack of clarity in whether the relationship between researcher and participants had been considered in one study); no or very minor concerns about the coherence of the findings were identified; minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden and the Netherlands) and so may have had a different cultural experience of healthcare; minor concerns about adequacy as the evidence was limited to very few studies presenting each perspective of the finding. There was a judgement of low confidence in this finding due to the concerns regarding the methodological concerns, partial relevance and adequacy of this finding.

Review finding 3c: Stroke survivor/family member expectation to return to ‘normal’ after early supported discharge[5, 8, 11, 15, 20, 22, 28, 33, 39, 40, 44, 49]

Stroke survivors and family members experience a complex range of thoughts and emotions after stroke which influence their ability to engage with the early supported discharge process. Initially after stroke, motivation to return to how their life was before the stroke was high. This understanding was moderated by the amount of recovery the person was experiencing, with people being more motivated when they could see bigger changes towards this return to ‘normal’ and less motivated when they could not see these changes (‘At discharge people spoke of expectations that this recovery would continue. As Mr Wilson, aged 80, discharged from the Stroke Rehabilitation Unit after a hospital stay of 67 days said: "Things like that I'm aiming for; to try and do a lot of the jobs that I used to do - you know what I mean? I mean if I feel like I want to do a bit of do-it-yourself well why not? If I recover enough I'll do it..."’ [11]). When stroke survivors and family members were informed about early supported discharge, the thought of many was that they could return to their usual way of life (“I usually go to the tobacconist and bets on horses and I expect that I'll continue doing that. It's just a small hill to get up and shouldn't be too hard for me. What's going to happen is that you'll get back to what you were doing before." - Participant 8[28]). This was associated with the hope that they would return to being their former self ("I'm hoping and hoping and hoping, because I don't know yet, I hope that I, that I can be completely recovered, as before." - Participant 7[28]).

This idea was often at the forefront of stroke survivors' thoughts, but behind this was anxiety at whether this was possible or not which was coupled with frustration when the evidence indicated they were not returning to the normality that they wished for ("Yes, it's a bit like, you can't just go out and shop (for groceries), I can't just sit in the car when I want to, it will make me angry. Yeah, that I can't do it, I don't get sad, or depressed, it's not that, I will just be angry I imagine. Yeah, and this leg here, this damned leg, // ... when you are used to being able to manage and do everything by yourself..." - Participant 1 [28]). Their achievements were weighed against the areas that had not gone as well ('The participants compared their performed after stroke with their previous performance or with the performance of others who had suffered stroke. Such comparisons often affected their self-esteem negatively, as shown in some of their comments: "not so talented", "reduced", "stupid", and "not too handsome to being with". Their self-perception was affected by success or failure.'[39]. People dissociated their sense of self from their body, associating their body as the barrier to returning to normal life seeing their body as "changed" and their body as a "door" to the practical and social world that they sometimes could not reach[39]. People were unsure on what they could hope for and what the future held, knowing what their goals were but not knowing whether they could achieve them due to their body and the energy it took to control it[33]. The effect this had on their relationships with others was significant (see review finding 4b, 4c and 4d – the one about relationships). Healthcare professionals agreed that there was a significant number of challenges the person would have to face associated with their return home that may not have been apparent while in hospital ("The 'body function-oriented' institution-based rehabilitation, combined with the constructed environment, covers up most of the client's cognitive problems. So when a client returns home, they are up for a challenge. Guaranteed." - Neuropsychologic, outpatient rehabilitation[44]). The expectation of returning to their previous life provided motivation but also high expectations that could precipitate anxiety and frustration if this was not perceived to being met. This was exacerbated by the thoughts that they could be burdening other people. All of these would be felt throughout the early supported discharge process.

Explanation of quality assessment: minor methodological limitations (due to a combination of problems with a lack of clarity in whether the relationship between researcher and participants had been considered, one study with a lack of information about whether ethical concerns were addressed and one study where it was unclear if the data analysis was sufficiently rigorous); no or very minor concerns about the coherence of the findings were identified; minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Denmark, Norway, the Netherlands and Australia) and so may have had a different cultural experience of healthcare and for some studies discussing home rehabilitation rather than specifically early supported discharge, which were both deemed unlikely to have a large effect on the finding; no or very minor concerns about inadequacy as the evidence is sufficiently deep. There was a judgement of moderate confidence in this finding due to the concerns regarding the methodological concerns and partial relevance of this finding.

Review finding 3d: Stroke survivor/family member/healthcare professional expectation that the family member will help[5, 11, 21, 33]

A theme identified in multiple studies was about the involvement of the family member. Where family members were involved in the life of the stroke survivor, there appeared to be an assumption by everyone that they would be supporting the stroke survivor once they got home ('I have my wife to look after me'. (13).'Yes, because I have a wife at home. She's getting more and more free time, so she can help me.' (3). 'You always do (help and support) when you have lived together for many years.' (16).[33]). Healthcare professionals noted that if a person was not independently functioning, the presence of family was considered essential before early supported discharge could be considered[21]. However, this process starts a change in the relationship between the stroke survivor and the family member, with the family member transitioning to being a carer for a period of time (see review finding 7a).

Explanation of the quality assessment: moderate methodological limitations (due to a combination of problems including a lack of clarity in whether the relationship between researcher and participants had been considered, one study where it was unclear if ethical issues have been considered and one study where the rigor of the data analysis was unclear); no or very minor concerns about the coherence of the findings were identified; minor concerns regarding relevance due to some studies discussing home rehabilitation rather than specifically early supported discharge; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to the concerns regarding the methodological and relevance concerns of this finding.

Review finding 3e: Stroke survivor/family member expectation that they will work with professionals experienced in stroke[12, 20, 28, 40, 44]

Stroke survivors and family members expected that the healthcare professionals working with them would have a significant amount of experience with stroke and would be able to provide them with information and guide their care effectively ("It is sensible that people are coming who know what they are doing with this kind of stuff." - Participant 8[28]. This was often reported as being the case for early supported discharge professionals. However, this is less likely with other community teams, including primary care. This led to feelings of uncertainty ("When there are different opinions among the doctors, it's problematic. It's very important to give the patient a feeling of security and knowledge about what to be done if this or that may occur. (Participant 4)."[40]). Patients expected that specialist knowledge would be obtainable from multiple sources, including their primary care doctor. However, this was not obtainable in some cases. Stroke survivors found that the amount of experience within primary care was diverse, but also not transparent[44].

Healthcare professionals agreed that there was differences between the experiences of people in specialised and primary care (‘Healthcare professionals in specialised care had a clear assumption of the needs and were mainly pleased with their organisation for including a follow-up with a nurse at 1 month and a physician at 3 months after discharge. In contrast, physicians in primary care were primarily concerned with the medical issues and were less clear on their understanding of the broader needs.’[20]). Professionals linked this to differences in which patients professionals normally seen ("How can you build expertise when you treat three to four stroke clients a year?" - Physical therapist, institution-based rehabilitation[20]). General practitioners reported finding it difficult to know who they needed to refer to for expert opinion ("When a client needs home-based stroke rehabilitation, I do not know to which professional I need to refer him to. Everybody <professionals> says they can deliver the treatment, but I do not know if they really can and who is the best." - General practitioner, primary care[44]).

Explanation of the quality assessment: minor methodological limitations (due to a combination of problems with a lack of clarity in whether the relationship between researcher and participants had been considered, one study where it was unclear if the recruitment strategy was appropriate and one study where it was unclear if ethical issues have been considered); no or very minor concerns about the coherence of the findings were identified; minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Norway and the Netherlands) and so may have had a different cultural experience of healthcare and for some studies discussing home rehabilitation rather than specifically early supported discharge, which were both deemed unlikely to have a large effect on the finding; no or very minor concerns about inadequacy as the evidence is sufficiently deep (provide themes, with elaborations and examples). There was a judgement of moderate confidence in this finding due to the concerns regarding the methodological concerns and partial relevance of this finding.

Review finding 3f: Beliefs about intensity of therapy[5, 7, 12, 15, 21, 33, 40, 44, 47]

There was inconsistency in people's beliefs and experiences regarding the intensity of therapy that would be provided during early supported discharge. The majority of studies reflected that early supported discharge led to more intense or sufficiently intense therapy. This was achieved through a few mechanisms, including the additional activity from being involved in activities of daily living at home that would not normally be achieved at hospital[44] and by team members being available at a much higher frequency than they could be when split between more people in hospital[12]. Early supported discharge was viewed as achieving a more person centred practice without compromising the intensity[5].

However, people in some other studies indicated that there was insufficient therapy ('Well, what I think, well I think they should have had a bit longer time.' (50).[33]). Staff described that a possible disadvantage could include reduced intensity of rehabilitation compared to hospital[21]. It was identified that there may be people who need more intensity than an outpatient programme could provide and people for whom a home environment is more suitable who could not receive the care they need ('Patients who need more intensity than an outpatient programme could provide or those for whom home environment is more suitable, fall into a black hole at the moment'. ESD Team Lead, 29[5]). Overall the opinion on whether intense therapy could be maintained with early supported discharge was unclear, even though there was a belief that this care should be as intense and more person centred.

Explanation of the quality assessment: moderate methodological limitations (due to a combination of problems including a lack of clarity in whether the relationship between researcher and participants had been considered, one study where it was unclear if ethical issues have been considered and one study where the rigor of the data analysis was unclear); no or very minor concerns about the coherence of the findings due to the theme of the finding being that inconsistency is present in the finding and highlighting the need to consider this; no or very minor concerns regarding relevance; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to the concerns regarding the methodological concerns of this finding.

Review finding 3g: Beliefs about the cost of early supported discharge[12, 15, 25]

The thoughts on the cost of early supported discharge were a moderator for whether people consider the service appropriate to use or not. Stroke survivors believed that by using early supported discharge they possibly freed up beds that could be used by people who needed it. Healthcare professionals had a variety of thoughts on the cost of early supported discharge, with some believing that the cost was equivalent to that delivered in the hospital and reduced the number of days that people were in hospital making it more likely to be reducing cost in some places[25], while others doubted this considering that the costs of additional staff required to complete the service may be more[15]. Some ways were suggested for reducing the cost of the service, including employing more staff at support worker levels rather than employing staff at high bands who may not always be required[25]. The information on the cost effectiveness of early supported discharge is not well understood.

Explanation of the quality assessment: moderate methodological limitations (due to a combination of problems including a lack of clarity in whether the relationship between researcher and participants had been considered, one study where it was unclear if ethical issues have been considered and one study where it was unclear how appropriate the recruitment strategy was for answering the question); minor concerns regarding coherence due to variety in understanding about cost between different healthcare professionals; no or very minor concerns regarding relevance; minor concerns regarding adequacy due to there being few studies that explored this factor in the depth required for a more complete understanding. There was a judgement of low confidence in this finding due to the concerns regarding concerns with the methodology, coherence and adequacy of this finding.

Review finding 4: The stroke survivor's experiences that need consideration

This theme included 3 subthemes: Loss of independence – sometimes needing support; Changing relationships with their partner, friends and children/grandchildren; The future – What is it going to look like? Will I have another stroke?

Review finding 4a: Loss of independence – sometimes needing support[28, 33, 39]

Stroke survivors can experience significant changes to their lives after stroke, even if people are able to meet the criteria for early supported discharge ("...I've always been independent // so it is a completely new situation and I can't know how it is going to be // it might be great or it can go badly." - Participant 6[28]). This was often associated with a loss of independence and requiring support from family members or friends and healthcare professionals that they would not have required previously. This was often associated with feelings of loss ('The thing is that you feel worthless, in fact, have to have help with everything'. (4).[33]). The changing roles of other people important to them in their life furthers this feeling. This produces a feeling of helplessness ("I want to be independent (altered voice from eager to monotonous), but when you have suffered stroke, there is nothing to do about the situation, which often makes me feel [was not able to express himself fully]."[39]).

Explanation of the quality assessment: minor methodological limitations (the majority of studies had no concerns with risk of bias, with one having limitations with a lack of clarity regarding the exploration of the relationship between the interviewer and the participants and whether the data analysis was sufficiently rigorous); no or very minor concerns regarding coherence; minor concerns about relevance due to all of the contributing studies representing the views of people from countries that were not in the United Kingdom (Sweden and Norway) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding the adequacy (while the number of studies were low, the data was considered sufficiently rich to explore the issue). There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 4b: Changing relationships with their partners[7, 11, 20, 22, 33, 40], friends[11, 33, 39, 40] and children/grandchildren[11, 21, 22, 28, 39, 40]

Stroke survivors and people they are in relationships with (from the views explored in these studies, either married or long term partner) can experience significant changes in their roles after the stroke, with the partner becoming a caregiver (see review finding 7) and the stroke survivor becoming a patient who needs support ('Yes, because I have a wife at home. She's getting more and more free time, so she can help me.'[33]). Emotional changes after stroke can lead to further changes that can add strain to the relationship which was hard for the stroke survivor ("My wife says that I am changed. Since, after the stroke I have changed in that case [Resorting to impatient outbursts more often than before the stroke]. I have, yes she certainly feels my behaviour changed. I think so too, and I think I was a nicer person before, because I stir myself up easier and it is easy to say not actually ugly things, but words you should not have said."[22]) and the partner ('Well, he can get so angry, he can't speak properly. And sometimes I also have to get angry and say if you don't calm down a bit, I'll get sick too. Then I won't cope any longer. What'll we do then? I know, it won't work, he says.' [33]). This experience varied depending on the relationship the partners have before their stroke, with some people being more worried about the future than others, including regarding the risk of future strokes ('Worrying about it coming back will do no good. You can't live like that, eh? I mean, you just gotta move on, don't you?' Inger (partner).[22]). In time partners adapt to the change in their routines and made new divisions of labour to ensure everyone participates ("We do a little bit at the time. One day it's dusting and the next it's vacuuming and 1 day we mop the floors together. That's how we manage ...' Elin (patient). 'And you know what? The other day we cleaned the windows - Elin moved the stuff in the window-sills and I did the cleaning and we had quite a good time, didn't we?' Ejnar (partner).[22]).

A difficult challenge identified was balancing the stroke survivor completing tasks and the partner helping to complete those tasks. It was highlighted that partners should not become ‘proxy therapists or parents’ to the stroke survivor and should remain their partner. However, this is difficult as there is also a feeling that their role is ‘to nudge, challenge and support the person in pursuing challenges at the right time’[22]. Some also felt like the stroke survivor was less likely to do their rehabilitation if the partner suggested they did it than if the healthcare professional suggested it('Well, it's your own relative, see. I don't think she does what I tell her like when "they" say it.' (61).[33]). This changing relationship changes both of their relationships with others, as the stroke survivor experiences the disabling nature of society, the family member also experiences a different element of that and how it affects their relationship with others[33] (see review finding 4c).

The stroke survivor’s relationship with their friends often changes. This is due to a mixture of factors including the stroke survivor’s ability to interact with the outside world due to a mixture of less physical and emotional access, reduced ability to withstand conflicts and reduced ability to manage familiar activities with others[39]. This also included the friend’s ability to adapt to the change ('That there are friends and acquaintances that can't tackle it. A man who was big and strong one day and then the next day he has to have help with everything. Then the mates wonder. Well, they simply can't cope with it, so they gradually drop out.' (55)[33]). The additional fatigue coupled with challenges engaging with the world after their stroke can make it an isolating experience for a stroke survivor. The changing pace of activity required after stroke was also a barrier to previous activities (see review finding 5d – the one about adaptations to life).

However, this experience varies between people. Some stroke survivors may decide it Is not possible for them to lose that social engagement and so have to find alternative ways to do it (‘A familiar participant in her forties described her struggle as a mother, "You just have to find the strength. I have to say, if you are there or not, you just have to find your hidden power even though you do not know where to take it from." Giving up was simply not an option with children who still needed her on a daily basis.’[39]). Others may return to work, which provides additional challenges but also encourages their socialisation ("To get something to do and mingle with my colleagues, I've many nice co-workers, who I like to talk and socialise with. Just to get out of bed, catch the bus, get to work and be where you were before. (Participant 5)."[39]). The experiences of stroke survivors in socialisation is varied, but there are barriers present that make this harder then it would have been before their stroke.

For parents and grandparents, they found that their relationships with their children and grandchildren changed after their stroke. For some their children and grandchildren may become carers to support them and so undergo a similar transition to partners in this regard and gain the challenges associated with this (see review finding 7). For parents and grandparents who are still caring for their children, the challenges of adapting to their life after stroke and providing the care required were significant[39] ("He withdraws a bit. And he, yes, he does not express it so explicitly (crying), but I do not have the same contact with him, like before. And he knows I can't (crying), eh (swallowing), that grandfather can't take him out fishing (voice cracking) fishing again."[40]). For those receiving support from their children, the feeling of being a burden or that they and their body were no longer good enough for them was noted[39, 40]. They worried about intending important events in the future, such as holidays and weddings[22].

However, having children and grandchildren was also a motivation and a source of practical (...the computer, paying bills, my son made sure I did it (made sure the numbers were entered correctly), my son helps me." - Participant 5[28]) and emotional (("…and my daughter's there now too, so that's also a comfort". - Participant 6[28]) support. Worrying about future events meant that there were events in life that gave home for the future[22].

Explanation of the quality assessment: moderate methodological limitations (due to it being unclear whether the study considered the relationship between the interviewer and the participant); no or very minor concerns regarding coherence (while variations were seen, these are likely reflective of the varied relationships that partners can have and still support the theme that changes occur); minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Norway, Denmark and Australia) and so may have had a different cultural experience of healthcare and for some studies discussing home rehabilitation rather than specifically early supported discharge, which were both deemed unlikely to have a large effect on the finding; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 4c: The future – What is life going to look like? Will I have another stroke?[7, 8, 11, 18, 20, 22, 33, 39, 40]

Stroke survivors were commonly concerned about what the future would be like after their stroke. People struggled to plan for future events due to the uncertainty of how their life currently is, how their life may be more limited than before[8] and what could happen(Lou, 2017 #1760}. The difficulty is knowing whether they are going to recovery fully or not added to this uncertainty (But, you know, you can't rush it. Time has got to sort it out hasn't it? Which it has. So if I get some physio, or help um I'm sure eventually, I mean to say maybe not 100% because something perhaps is dead...".[11]).

Another concern highlighted in multiple studies was the idea of the stroke happening again ('But there's that worry all the time that it can come back again.' (58).[33]). This concern appeared to be common between stroke survivors and their family members. In some cases this led to people changing their behaviour to adopt lifestyles that they believed would reduce the risk of another stroke[7]. However, the risk of another stroke left a feeling of uncertainty over their life that was difficult to deal with ("R: Er...the uncertainty. Even now I'm not sure whether one should expect another stroke or whether you should accept that it's behind you and it's unlikely to happen again ... The biggest problem is not knowing what the future holds. Other than that I can cope with the ... ah, 'cope' [seeming to pass comment on his choice of word as ironic] with the little things that are evidence from the stroke. I'd be quite happy to copy with those little things for the rest of my life, but it's the uncertainty of what might happen in the future. I: Yes. Have the doctors talked to you about ... about that?" R: No they haven't. I haven't asked. Perhaps that's the reason they haven't mentioned it. Perhaps they feel that I'm quite lucid and comfortable with it but I do feel a little bit uncertain[11]). Some faced this by being determined to reject the worries ('Worrying about it coming back will do no good. You can't live like that, eh? I mean, you just gotta move on, don't you?' Inger (partner).[22]). Specific for people who were eligible for early supported discharge there was a feeling of gratitude that their stroke was more severe, which added to the motivation to change their life and the fear that it could be worse next time[39]. The fear of future strokes was a constant fear during the early supported discharge period.

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of unclear reporting of exploration of the relationship between the interviewer and the participant and whether the data analysis was sufficiently rigorous); no or very minor concerns regarding coherence; minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Norway and Denmark) and so may have had a different cultural experience of healthcare and for some studies discussing home rehabilitation rather than specifically early supported discharge, which were both deemed unlikely to have a large effect on the finding; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 5: Involving and supporting family

This theme included 4 subthemes: from family member to carer; not involved in decision making; lack of training for carers; limited support for carers.

Review finding 5a: From family member to carer[21, 22, 28, 33, 44]

Family members who are involved in the care of a stroke survivor can experience a large change in their life where they transition from being a family member to helping to provide care and support to their family member who has had a stroke. Family members provide a sense of security to stroke survivors helping them to feel more confident ('Well, first of all, I just didn't feel that ill. And second, I knew Emma would be around. And that means a lot...a sense of security'. (Karl, patient).[22]). Practical tasks may be taken on by family members (...the computer, paying bills, my son made sure I did it (made sure the numbers were entered correctly), my son helps me." - Participant 5[28]). This can put a lot of pressure on family members ('You do the things you think you're good at. I've always looked after the outdoor things, the yard and the car and things like that. She's never bothered about that. She's done cleaning and tidying. It was natural to do what you liked doing.' (61). 'All of a sudden, I had to do everything.' (56).[33]). These people are also associated with the stigma that can be experience by stroke survivors which can make life harder ('For one thing, you became an outcast yourself when such a thing happens. You don't know what has happened.' (56).[33]).

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant and about the rigour of the data analysis in one study); no or very minor concerns regarding coherence; minor concerns about relevance due to all of the studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Denmark, the Netherlands and Australia) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 5b: Not involved in decision making[21, 33, 34, 44]

Even though family members were seen to be important in deciding whether someone could use the early supported discharge services, family members often found that they were not included in the decision making process ("They <clients and caregivers> hear: "It was a stroke", and the next second they are home again. Caregivers are not included at all." - Case manager 1, primary care[44]. This could lead to them feeling like they were forced into a situation where they may need to take more responsibility ('And ask a person who's lying in bed in hospital if he wouldn't like to go home, I don't believe such a person exist. And then I could hardly refuse could I?' (61).[33]). Healthcare professionals reported in one study not considering a lack of patient and carer consent to go home as a barrier to early discharge[21].

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant and about the rigour of the data analysis in one study, lack of information about the ethical considerations in one study and no clear statement of findings in one study); no or very minor concerns regarding coherence; minor concerns about relevance due to all of the contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, the Netherlands, Canada and Australia) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 5c: Lack of training for carers[7, 33, 47]

Family members who were supporting with care also reported that they did not receive enough training and information for the role they would need to do ('No, they came with that paper and said sign here. I think you should take part in the training.' (8)[33]). Family members may need to provide support with problem-solving that they may not know how to do in a way that manages the complex interaction of encouraging the person's autonomy while also providing the support they need[47]. However, some people found that they were taught by the early supported discharge team as the process carried on which helped ('I've done a lot of training with him at home...first with the team and then I've taken care of it...so we keep going every day. And we still do.' (54).[33]).

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant and about the rigour of the data analysis in one study, lack of information about the ethical considerations in one study and no clear statement of findings in one study); minor concerns regarding coherence (due to one report that the training was adequate); minor concerns about relevance due to the majority of the contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of low confidence in this finding due to concerns with methodological limitations, coherence and the relevance of this finding.

Review finding 5d: Limited support for carers[7, 15, 22, 33, 34]

In addition, family members agreed that there was limited support available for carers. Carers were often left exhausted and physically strained, having to undertake tasks that the other person may have done initially on top of their usual responsibilities[7]. It was noted that the awareness that the early supported discharge team would contact the person a few days after discharge was very important[22]. This absence of support is also felt from friends who tended to focus on the stroke survivor instead of the carer ('Everybody rings and wonders how he is, but no one asks how I'm coping with the new situation.' (55)[33]). People found that the support provided by healthcare providers was really important and that working in a team with them and the stroke survivor was appreciated[34]. Family members were comforted that the team were '…only a phone call away'[22]. The pressure experienced by the family member is significant and so ensuring that support is available is critical.

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant and about the rigour of the data analysis in one study, lack of information about the ethical considerations in one study and no clear statement of findings in one study); no or very minor concerns regarding coherence; minor concerns about relevance due to the majority of the contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Denmark, Canada and Australia) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of low confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 6: Making home (and life beyond) safe and enriching for rehabilitation

This theme included 5 subthemes: wanting to return home as soon as possible balanced against feeling safe in hospital; home as a place of familiarity; home as a new training ground/work place; suitability of home/equipment and returning to work.

Review finding 6a: Wanting to return home as soon as possible balanced against feeling safe in hospital[7, 8, 15, 21, 22, 25, 28, 33, 47, 49]

The people in the studies reported a mixture of feelings regarding returning home that varied from wanting to return home as soon as possible[7, 8, 15, 21, 22, 25, 28, 33] to feeling safe in hospital and so not wanting to return home too early [8, 21, 28, 47]. A lot of people felt confident in returning home and that if they could ‘get out’ then they would feel better ('There's that attitude in a lot of people that once they're home, they'll begin to really do things. I think that if people were at home with the kind of support that I had, I get the feeling that they would have been mobile much, much quicker.'[8]). There was a feeling that they needed to return home and it would be the optimal recovery environment, which was shared by family members and some healthcare professionals[15]. Stroke survivors also saw this as helping the healthcare service and allowing beds to be available to people who need them ('To be discharged earlier would bring more resources for the use at the hospital and it would help me immensely, but I think you would improve more so being in your own home surroundings. I think that you can get well better by being in your own home situation and also as I said earlier, it just brings less pressure to the hospital. It gives them time to get onto something else. - Patient 4'.[21]).

Healthcare professional opinion was diverse. Staff noted the disadvantages that could come from being discharged home too early, such as possible readmission to hospital due to illness, unsuitable home environments that may make their functioning worse, and reduced levels of confidence from being away from hospital ('I think just probably ... feeling less confident in her abilities ... In the hospital, everything was taken care of and then having to go home and fend for herself ... a bit daunting - Health professional 1'.[21]). This lack of confidence was reflected by some stroke survivors ('Before I actually came out of the hospital, before coming home, I panicked slightly, and I thought going through my mind, how am I going to get around with the walker? How am I going to get to the cooker? Will it fit? You know, all the little things, I'm going through the house in my mind you know that kind of way, and I panicked for a few hours "I'll never manage, what am I going to do?"'[8]). Some healthcare professionals agreed that, while initially patients felt they needed more frequent follow-up, this normally reduced over time indicating that they could produce that feeling of safety initially, but that this was eventually not needed ("When it's time for the early discharge from hospital they want you to make frequent home visits, but once they're at home they're not so anxious any longer. The patient is also aware of the fact that the important thing is not the times when I come but what they themselves do between the home visits."[47]). The sense of safety provided by the early supported discharge team’s visits was highlighted by stroke survivors ("...it feels secure to know that they are coming home, that they, I know that on Tuesday that she's coming at 10 am, or whatever time it is (appointed time). So I know that they are coming here (to my home)." - Participant 3[28]).

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of unclear reporting of exploration of the relationship between the interviewer and the participant, whether the data analysis was sufficiently rigorous and a lack of clear statement of findings); no or very minor concerns regarding coherence (while variations were seen, these are likely reflective of the balance of feelings people could have after stroke and represented a dichotomy of thoughts that are present at different weightings, rather than separate concepts); minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Denmark and Australia) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 6b: Home as a place of familiarity[8, 11, 21, 28, 40, 49]

People after stroke referred to home as a place of familiarity where, once they returned, they would start to feel more like themselves again ('When you're at home, daft things like making a cup of tea, watching a bit of telly, watching your neighbours come in...It all lifts you.'[8]). Returning home would allow them to have access to their own things and see the people they wanted to see ("...living in my own house and doing my own stuff and being able to communicate with the rest of the world, because I don't have any internet access here." - Participant 10[28]).

However, there was a thought from some that while being home in a familiar situation was initially exclusively positive, as time passed it became more of a hindrance which may be linked to the limited social capacity early on after stroke and a need for long-term follow-up[40]. There were limited studies that investigated people's thoughts after the end of the early supported discharge process, which made this difficult to expand on more.

Explanation of the quality assessment: moderate methodological limitations (due to unclear reporting of exploration of the relationship between the interviewer and the participant); no or very minor concerns regarding coherence; minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Norway, the Netherlands and Australia) and so may have had a different cultural experience of healthcare and for some studies discussing home rehabilitation rather than specifically early supported discharge, which were both deemed unlikely to have a large effect on the finding; minor concerns regarding adequacy due to the limited information available at the changes in the long term after early supported discharge. There was a judgement of low confidence in this finding due to concerns with methodological limitations, the relevance and adequacy of this finding.

Review finding 6c: Home as a new training ground/workplace[22, 28, 33, 44, 49]

Returning home for early supported discharge created a new place full of challenges that required solutions. This meant that people sometimes felt like home was a new training ground or workplace ('I've done a lot of training with him at home...first with the team and then I've taken care of it...so we keep going every day. And we still do.' (54).[33]). This allowed for a person-centred approach as every challenge that was identified could be solved as they appeared. However, problems that may not have been noticed in the hospital would often become apparent in this setting ("The 'body function-oriented' institution-based rehabilitation, combined with the constructed environment, covers up most of the client's cognitive problems. So when a client returns home, they are up for a challenge. Guaranteed." - Neuropsychologic, outpatient rehabilitation[44]). However, unlike the hospital, homes are not necessarily ideal conditions for these activities which produced additional challenges that may not necessarily be transferrable ("We did shower training at the ward, too, so that was pretty much the same kind of training, but the transfers were different because they had a bathtub, which was quite high. It became a different experience, even if the activity of showering was the same."[49]). The effect of seeing home become this workplace was not explored. However, one person saw their home activities and responsibilities as a barrier to rehabilitation rather than a facilitator ("Yeah, I've got the kids stopping me now, // so you get reminded a fair bit. I've already been (reminded), they say that 'you should think about yourself', there's lots of that. // So you have to take it a bit easy. // They are firm (with me), they're going to be (firm with me) ... // I am going to listen to them, // I have to, // it isn't greater (to be told what to do by your kids). I'm not hurt by it, but, you know, when you aren't used to it." - Participant 1[28]).

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of unclear reporting of exploration of the relationship between the interviewer and the participant and whether the data analysis was sufficiently rigorous); minor concerns regarding coherence (due to the view that home may be a barrier to rehabilitation rather than a training ground that encourages it); minor concerns about relevance due to all of the contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Denmark and the Netherlands) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations, coherence and the relevance of this finding (with the limitations due to coherence being seen as a minor difference and not sufficient enough to reduce the overall quality rating).

Review finding 6d: Suitability of home/equipment[7, 21, 28, 33, 49]

As early supported discharge is prepared for, discussions need to be had on the suitability of the home and whether additional equipment is required. While home can provide additional challenges that may help rehabilitation, it was noted that homes may not always be suitable and may be a problem that hinders rehabilitation instead. Discussions about adaptations and equipment that would be required was seen as necessary prior to discharge[21]. People were often provided with adaptations that helped them to return home and this required careful consideration due to how much work it may require to achieve this ('The most troublesome things were the toilet and the shower. As for the bed, he learnt to sit up quite soon, actually, but it's hard. We had to take up all the rugs; he had to go with a walking frame on wheels indoors. It's difficult.' (50).[33].

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of unclear reporting of exploration of the relationship between the interviewer and the participant and whether the data analysis was sufficiently rigorous); no or very minor concerns regarding coherence; minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden and Australia) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 6e: Returning to work[18, 39]

Two studies discussed returning to work during and after early supported discharge. The experiences of this varied from seeing a lot of benefit from returning to normality (as with returning home) but also that, due to the changing pace of life that is seen with people during early supported discharge anyway, that this can lead them feeling like they may be less able to do their job (“At work, for example, if I find myself slow and realise I did the work a lot faster before. Nowadays it frustrates me. I don't like it , you know.”[39]). People may find that new features from after their stroke may make work more demanding than before, including pain ("Pain can just come when I'm running around with a patient, for example. Being in the middle of something and the patient puts pressure on me, right, requiring me [to respond] cognitively. That's what happens at work. The patients require me to be there for them [practically, cognitively]; and it is certainly what I'm afraid of, to meet those requirements again."[39]) and fatigue ("I guess I felt prepared enough because they [healthcare staff] had said that I could expect some fatigue, but I wasn't prepared for how it turned out ... they hadn't said that."[18]). While others found that they were unable to return to work and require more time before they can return if at all.

Explanation of the quality assessment: no or very minor methodological limitations; no or very minor concerns regarding coherence; minor concerns about relevance due to the contributing study reflecting the views of people from Norway instead of the United Kingdom and so may have had a different cultural experience; minor concerns regarding adequacy due to the limited number of studies exploring this theme. There was a judgement of moderate confidence in this finding due to concerns with the relevance and adequacy of this finding.

Review finding 7: The need for psychological support

This theme included 6 subthemes: motivation; control; loss; mild stroke and feelings of invisible disability; adapting to life being different and the need for psychological support.

Review finding 7a: Motivation[8, 18, 22, 28, 39, 40, 47]

Motivation and how to maintain this was commonly discussed. A common experience discussed was an initial hope filled period where people were seeing significant improvements with rehabilitation that motivated them to do more[22, 39, 40]. However, if these improvements are not as apparent, start to slow down or are not to the amount that the person would want in their journey to return to ‘normal’, then this will reduce motivation[8, 40]. One person felt more motivated when they were reminded about what happened in the past and how much progress they had made ("You remember the way it was in the beginning. You couldn't do this, you couldn't do that. But now you can actually dress yourself and cook and do this and that. So you see, you've improved. It usually helps the patient to get on with his life."[47]). Stroke survivors described the need for the ‘strength’ to carry on and that if this is not present then this may lead to helplessness ('I think an awful lot of it has to do with the patient. The type of patient that you have. You either have somebody who's helpless and no strong enough to face it...but...if you can make yourself, do it! You have to make yourself; same as you have to make yourself get up and walk.'[8]).

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of lack of information exploring the relationship between the interviewer and the participant, whether the data analysis was sufficiently rigorous and there being no clear statement about the findings from one study); no or very minor concerns regarding coherence; minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Norway and Denmark) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 7b: Control[8, 18, 22, 28, 39, 40, 49]

After a stroke, the experience of control starts to change. Early supported discharge is an opportunity to restore control by being in their home and their own environment ('It's just more relaxed...Like, at the hospital I sit in the chair, right? At the patient side of the table. But at home it's different. It's my home ground so the roles are a bit different. She's the visitor. That puts me more in control. In a way.' Jakob (patient).[22]). However, recovering from a stroke is associated with a wish to gain more control of their body and their life ("I want to be independent (altered voice from eager to monotonous), but when you have suffered stroke, there is nothing to do about the situation, which often makes me feel [was not able to express himself fully]."[39]). Some parts of their life after a stroke is not controllable and can lead to more distress ("It was just a lot of pain. One pain comes, and then the next and the next. Well you can manage one [pain] and then another, and then you are way down at the bottom and finally, you cannot go any deeper. Then you have endured so much pain and when you then get up, oh, yes, you are alive after all so you are back in the real world."[39]). Ways of increasing control can help the person to feel better and be more engaged with their rehabilitation and coming home can be an important force towards that.

Explanation of the quality assessment: minor methodological limitations (due to half of the studies having minor limitations and half where the information regarding whether the relationship between the interviewer and participant were considered was unclear); no or very minor concerns regarding coherence (as the findings were different parts of the same experience); minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Norway and Denmark) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 7c: Loss [33, 39]

The combination of factors discussed in review findings 6a-c, contribute to a feeling of sadness and loss after stroke. As life has changed significantly there is a loss associated with what has changed. This is coupled with changes in emotionality that can come after a stroke, which becomes more apparent as time passes ('I could cry for no reason, it just comes.'[33]). Even when the person recovers physically quickly, there can still be factors that make it harder for them to act as they did before their stroke which can add to this feeling ("In my case, I have recovered physically pretty fast. I got a grip on, on that. But professionally [doing his tasks at work], I feel that I still have ended up in the second division."[39]).

Explanation of the quality assessment: minor methodological limitations (due to one study having minor limitations and one where the exploration of the relationship between the interviewer and participant was not clearly stated and the rigour in the analysis was unclear); no or very minor concerns regarding coherence; minor concerns about relevance as all of the studies represent the views of people from countries that were not in the United Kingdom (Sweden and Norway) and so may have had a different cultural experience of healthcare; minor concerns regarding adequacy due to information being obtained from two studies. There was a judgement of moderate confidence in this finding due to minor concerns with methodological limitations, relevance and adequacy (that were deemed to each have minimal impact on the overall quality of the finding).

Review finding 7d: Mild stroke and feelings associated with invisible disability[22, 39]

People after mild stroke, who may be eligible for early supported discharge, may experience feelings associated with having an invisible disability, where their experience of life has changed a lot and makes life more difficult in ways that other people may not notice or realise. This leads to a mixture of direct stigma where it is stated that ‘other people have it worse’ and shaming expression of the difficulties that people challenge and indirect stigma where the experiences of the person are ignored, and they are believed to be ‘the same as anyone else’. This is linked to engrained views of validity imbued into society which can lead the person to internalise these thoughts adding to their distress ("It actually would have been easier if I had visible signs of stroke, but I don't. Of course, I appreciate, but at the same time I sometimes wish (laugh). Can you see that I'm sick? (talking with feigned and intense voice). No, it is really ungrateful. You should not think of it that way, after all there are those who have it much worse than I."[39]). Due to the changes after stroke being parts that other people may not think about ('It's the little details that you never thought of in the humdrum of normal, everyday life'. (Oluf, patient).[22]) this may make this harder for others to see and so provide more sources of invalidity to their experiences. Providing people with support to show that their experiences are valid regardless of the severity of their stroke may help people to feel less distress.

Explanation of the quality assessment: minor methodological limitations (due to one study having minor limitations and one where the exploration of the relationship between the interviewer and participant was not clearly stated); no or very minor concerns regarding coherence; minor concerns about relevance as all of the studies represent the views of people from countries that were not in the United Kingdom (Denmark and Norway) and so may have had a different cultural experience of healthcare; minor concerns regarding adequacy due to information being obtained from two studies. There was a judgement of moderate confidence in this finding due to minor concerns with methodological limitations, relevance and adequacy (that were deemed to each have minimal impact on the overall quality of the finding).

Review finding 7e: Adapting to life being different[8, 11, 18, 21, 22, 28, 33, 39, 49]

After a stroke people have to adapt to their new experience of life, but how they do this varies between different people. This adaptation includes physical adaptations to the home (see review finding 6d) as well as changes in their behaviour. A lot of people find that they need to reduce the pace of their life to match what they are currently able to do[11, 18, 22, 28, 39]. A person’s perspective on the meaning of this can lead to different experiences. People who are able to work with their partner to manage changes in life can find additional solutions to problems ('We do a little bit at the time. One day it's dusting and the next it's vacuuming and 1 day we mop the floors together. That's how we manage ...' Elin (patient). 'And you know what? The other day we cleaned the windows - Elin moved the stuff in the window-sills and I did the cleaning and we had quite a good time, didn't we?' Ejnar (partner).[22]). Adapting to life can lead to frustration adding to distress ("At work, for example, if I find myself slow and realise I did the work a lot faster before. Nowadays it frustrates me. I don't like it, you know."[39]).

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant and about the rigour of the data analysis in one study); no or very minor concerns regarding coherence; minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Norway, Denmark and Australia) and so may have had a different cultural experience of healthcare and for some studies discussing home rehabilitation rather than specifically early supported discharge, which were both deemed unlikely to have a large effect on the finding; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 7f: The need for psychological support[5, 7, 39, 40, 47, 49]

With all of these factors taken into account, there is a need expressed by some stroke survivors for psychological support. Early supported discharge provided to key opportunity for addressing the emotional and cognitive challenges that stroke survivors experience, that may become more apparent when they return home ('Even people that have minimal physical impairments can be really anxious because their whole life has changed'. ESD Team Lead 29[5]). People seek appointments with psychologists to help them with this ("I intend to ask my GP about getting a referral to a psychologist, so I can sort out [emotional reactions]. To live on, I need to sort out my depression. (Participant 6)"[40]). The support that healthcare professionals can provide to the emotional wellbeing of people after stroke is significant.

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant and about the rigour of the data analysis in one study, lack of information about the ethical considerations in one study and no clear statement of findings in one study); no or very minor concerns regarding coherence; minor concerns about relevance due to the majority of contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden and Norway) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 8: Effective multidisciplinary teamwork

This theme included 6 subthemes: collaborative work between different professions and with the stroke survivor; the need for early supported discharge coordination; who is in the team? Staff requirements; relationship between the stroke survivor and early supported discharge professionals: encouraging their journey; trust; access to professionals when you need them.

Review finding 8a: Collaborative work between different professions and the stroke survivor[5, 25, 40, 44, 47, 49]

The early supported discharge team worked at it’s best when there was a collaboration between different professions, the stroke survivor and others involved in their care. Team members worked well together when they had a “passion for 'stroke'”[25]. Where there are parts of the collaboration that was not as close there was a feeling that care may become disjointed ('I think it worked well for those that were full time, but for those of us who were part-time, like myself, we shared it ... my gut feeling is that the team at that time ... may have found it a bit disjointed.'[25]). Healthcare professionals are important supports for each other, allowing them to come up with creative solutions to problems ("We can discuss the patients and ventilate things, otherwise it would be difficult. You get advice, support and a few reminders. Sometimes I have deep thoughts about various things, and then the team provides a lot of good support."[47]). If this collaboration does not work well then this can leave the stroke survivor to not feel the trust that they needed to engage in their rehabilitation ("They told me I had to wait because of some paperwork that had to be done. They put me aside for several weeks before I got started [with my follow-up treatment], while I felt it was very urgent for me. I lost some [valuable] time, and when I got started I had lost the glow, and they lost a little glow too, and then we were, not enemies, but I ... [sentence not completed]. (Participant 7)"[40]).

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant, about the rigour of the data analysis in one study, lack of information about the ethical considerations in one study and no clear statement of findings in one study); no or very minor concerns regarding coherence; minor concerns about relevance due to the majority of the contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, the Netherlands and Norway) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 8b: The need for early supported discharge coordination[15, 22, 34, 44]

One part noted to be important to the success of early supported discharge was to have a staff member who was responsible for coordinating the care received by the person. Someone who was accessible, had excellent clinical knowledge, an ability to work across service boundaries and that ability to act as a single point of contact and coordination was highlighted as a key factor for success of some programs[15]. Where coordination is not present there are more challenges in organising care[44].

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant, about the rigour of the data analysis in one study and no clear statement of findings in one study); no or very minor concerns regarding coherence; minor concerns about relevance due to all of the contributing studies representing the views of people from countries that were not in the United Kingdom (such as the Netherlands, Denmark, Canada and Australia) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and the relevance of this finding.

Review finding 8c: Who is in the team? Staff requirements[5, 12, 25]

The staff members who make up the early supported discharge team were discussed. While some members were taken as obviously included (for example: allied health professionals, physicians) a few members were emphasised. The first were rehabilitation assistants, whose role was emphasised as important and underrated. Rehabilitation assistants provided the ability to provide a closer level of support to participants and can provide a large amount of support to people[5, 12]. The importance of having social care professionals as a part of the team was also emphasised, with successful early supported discharge teams gaining a lot of help from social care professionals in providing care packages, while others that did not found this much more difficult which limited the number of people who could be supported significantly[5] ('With more health and social care type resources, they [the team] could get even more people home.'[25]).

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant, about the rigour of the data analysis and it being unclear if the recruitment strategy was appropriate for the aims of the research in one study); no or very minor concerns regarding coherence; no or very minor concerns regarding relevance; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations.

Review finding 8d: Relationship between the stroke survivor and early supported discharge professionals: encouraging their journey[8, 18, 22, 40, 47, 49]

The relationship between the stroke survivor and the healthcare professionals and the role that healthcare professionals play in their rehabilitation was raised. Healthcare professionals were initially ‘strangers’ who stroke survivors were forced to be together to restore them to their pre-stroke self who they may not want to come into their home ('Don't want strangers in and don't want them finding out stuff about me ... privacy would have been a big thing.'[8]. However, as time passes and they journey together the stroke survivor may find the healthcare professionals progressing towards friendship ('We became friends, they were my friends while they were here'.[8]). This strong relationship helps during rehabilitation to provide emotional support as well as support for their physical rehabilitation ('They were such nice girls, I looked forward to the camaraderie we had; we had great chats and craic.'[8]). Healthcare professionals played an important role in motivating and grounding the person so that they had realistic perspectives on their goals ("They [the municipal healthcare team] really came and stayed here and did something. They showed faith in positive development and supported me in that. It's important to convey that recovery can still happen, although the progress is slow. (Participant 1)"[40]).

Healthcare professionals saw their role to encourage the person to identify the challenges in their life and to work together while encouraging the person to find their problem-solving skills ("This man used to take a walk in order to place bets on the football games. Now he had problems writing his signature on the coupon and the goal for his walk had in some way lost its function. It was brought to my attention, and then I asked him if he wanted to practice writing his signature, something I would probably not have given priority to in a different situation. He wrote page after page practicing his signature. He was very motivated."[47]). This could be a challenging experience, but helped to restore control to the stroke survivor in a time when they may be feeling like this is lesser (see review finding 6b) ("There are patients who do things that almost scare you to death, but in his case, I was never really nervous that something was going to happen to him. He was a bit careless sometimes, but not without a degree of awareness. No, I was never nervous, I just think that it was great that he was in control and was a step ahead all the time. I did not try to stop him."[49]). Determining when to push the person to try more rehabilitation or when to take a break was also challenging (“Yes, there was a problem of some kind, and I felt it should really have been practiced one more time, but then I was afraid she might fail to accomplish the task, so I let it be. One stops there when the patient has done something that works."[47]). Developing a positive relationship, led by the stroke survivor but taking into account the guidance from the healthcare professionals was important to the success of the rehabilitation.

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant, about the rigour of the data analysis and it being unclear if the recruitment strategy was appropriate for the aims of the research in one study); no or very minor concerns regarding coherence; minor concerns about relevance due to the majority of the contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Norway and Denmark) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and relevance.

Review finding 8e: Trust[21, 33, 40, 47]

Stroke survivors and family members reflected that they trusted healthcare professionals to be experts and provide knowledge that they otherwise would not have ('Stuff I didn't understand myself, and I regarded them, of course, as experts.' (9).[33]). This included the choice as to whether they would be referred for early supported discharge ('...the hospital wouldn't send you home unless you could cope.'[21]). They also provided answers to support stroke survivors and family members throughout the early supported discharge process ('And then those girls came home and then I was able to get answers to all those questions I had.' (60).[33]). Healthcare professionals saw themselves as also providing links to people who could provide better answers than themselves ("We act like a kind of an ombudsman for the patient. We make it easier for the patients and you assist them in finding the right authority for their problems."[47]). Healthcare professionals were respected as experts during the early supported discharge process.

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant, about the rigour of the data analysis and it being unclear if the recruitment strategy was appropriate for the aims of the research in one study); no or very minor concerns regarding coherence; minor concerns about relevance due to all of the contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Norway and Australia) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations and relevance.

Review finding 8f: Access to professionals when you need them[11, 28, 34]

Stroke survivors and family members found that during early supported discharge they could have access to support from healthcare professionals whenever they need it. People reported healthcare professionals were “accessible” and that they were well informed of changes to the service provided[34]. People did report finding the initial communication more difficult at times and transferring of services could lead to miscommunications (C: Yes [laughing] yes. We just felt we were abandoned to start with and then I got a phone call saying that CART wouldn't be able to bring us home so it meant I had to dash round trying to find somebody ... We had to get a taxi home which was all a bit hectic wasn't it at the time? ... We felt we was just pushed out by the front door and left there on our own ... We haven't had any follow up from outpatients yet.[11]).

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant, about the rigour of the data analysis and, for one study, the research design not being appropriate to address the aims of the research and the data was collected in a way that did not address the research issue); no or very minor concerns regarding coherence (while there are different perspectives, these appear to be referring to different times in the process); minor concerns about relevance due to all of the contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden and Canada) and so may have had a different cultural experience of healthcare and for some studies discussing home rehabilitation rather than specifically early supported discharge, which were both deemed unlikely to have a large effect on the finding; minor concerns regarding adequacy (as the different perspectives of this theme have been found to have limited information supporting them). There was a judgement of low confidence in this finding due to concerns with methodological limitations, relevance and adequacy.

Review finding 9: Collaboration between other services

This theme included 2 subthemes: fragmented and inconsistent stroke care pathway and methods for increasing collaboration.

Review finding 9a: Fragmented and inconsistent stroke care pathway[5, 12, 25, 40, 44]

Healthcare professionals and stroke survivors reported that the stroke care pathway and where early supported discharge sat in that was confusing, in particular where it sits among other community services ('To be honest I am bit foggy about where Early Supported Discharge sits alongside intermediate care and re-enablement and how these are married up' Commissioning, 23[5]). This was also seen with the end of the process, where delays occurred with providing care packages ('Patients were bottlenecking up at the other end because their care packages wouldn't be ready; at eight weeks we'd still got these patients'. Service Management, 18[5]). People confused the early supported discharge service with being social care ('Sometimes they think we are social care and we are not...we have done things above and beyond what we are expected to do' ESD Team Member, 10[5]). There can also be tension between the different services because of this ('I mean that's potentially another issue. I guess that they might have felt that we were taking all their interesting patients, which is a difficult one isn't it? Because all the recommendations say that people should be treated by stroke specialist staff so that's one argument for the team in the first place, but I think they found it frustrating to think that what they were doing would differ from what we were doing.'[25]). This lack of clarity and collaboration can lead to problems considering that early supported discharge is a short term process and should be leading to referral to other services at the end ('I think the difficulty is actually, no service can operate in isolation, and particularly a service like this that has to refer onwards a patient; it's that whole kind of pipeline thing isn't it?'.[25]). Inadequate communication can also lead to duplications of assessments across the services[5]. This can lead to patients feeling less secure ("When there are different opinions among the doctors, it's problematic. It's very important to give the patient a feeling of security and knowledge about what to be done if this or that may occur. (Participant 4)."[40]).

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant, about whether ethical issues were considered and whether the recruitment strategy was appropriate in one study); no or very minor concerns regarding coherence; no or very minor concerns with relevance; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations.

Review finding 9b: Methods for increasing collaboration[5]

Healthcare professionals in one study discussed methods that could be used to increase collaboration between different services[5]. This included allowing staff to experience the approach by introducing a rotational element between people who could be involved with the team ('We could have some rotational element between staff so you can really share that sort of approach and the learning'. ESD Team Lead, 3[5]). It was also suggested that participation in meetings and common training events would be effective in improving the understanding about the services. If people understood the services more then it would be easier to collaborate.

Explanation of the quality assessment: moderate methodological limitations (due to the study providing limited information about the exploration of the relationship between the interviewer and participant and about whether ethical issues were considered); no or very minor concerns regarding coherence; no or very minor concerns with relevance; major concerns regarding adequacy (due to information only being provided by participants in one study and not achieving the richness needed to explore this theme). There was a judgement of very low confidence in this finding due to concerns with methodological limitations and adequacy.

Review finding 10: Providing care for as long as required

This theme included 2 subthemes: providing therapy for as long as it is needed and early supported discharge bridging the gap between inpatient and community services.

Review finding 10a: Providing therapy for as long as it is needed[5, 7, 12, 15, 33, 34, 40, 47, 49]

A discussion between participants took place as to how long therapy should be provided. Noting the person-centred nature of early supported discharge, some healthcare professionals believed that supported should not be provided for an arbitrary amount of time and instead for as long as the person needed it[12, 15]. However, early supported discharge services were often provided for a set amount of time, with the understanding that some people may need less or more support. Healthcare professionals agreed that at some point care should be transferred to other services that are able to help further[49].

Stroke survivors and their family often felt that additional time in the service would be helpful ('Well, what I think, well I think they should have had a bit longer time.' (50).[33]). Some people felt that a six-week cut off was ‘abrupt’ and not ‘continuous enough’[7]. Healthcare professionals experienced a different perspective where people may need more support initially but as time passes they require less support which naturally leads to the end of the process ("When it's time for the early discharge from hospital they want you to make frequent home visits, but once they're at home they're not so anxious any longer. The patient is also aware of the fact that the important thing is not the times when I come but what they themselves do between the home visits."[47].

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant, about whether ethical issues were considered, if the data analysis was sufficiently rigorous and whether the recruitment strategy was appropriate in one study); minor concerns about coherence (due to disagreements within the same population of healthcare professionals, while differences with stroke survivors may represent different perspectives rather than contradiction); minor concerns about relevance due to the majority of the contributing studies representing the views of people from countries that were not in the United Kingdom (such as Sweden, Norway, Canada and Australia) and so may have had a different cultural experience of healthcare; no or very minor concerns regarding adequacy. There was a judgement of low confidence in this finding due to concerns with methodological limitations, coherence and relevance.

Review finding 10b: Early supported discharge bridging the gap between inpatient and community services[5, 7, 12, 25, 28, 49]

Early supported discharge is an important opportunity to try and support the transition from inpatient to community services, which can be a problem experienced by stroke survivors whether they are taking part in early supported discharge or not. When successful, this service improves this transition ('Transfer between the services has improved and works in a much more seamless way'. Service Management, 4[5]). This ability can allow care to be continued beyond the limited time available for early supported discharge, and so could reduce feelings that people did not receive the care for long enough ("I could have assisted him more in the training, but there was not time, and he got follow-up training with the physical therapist."[49]). This could vary in how the service is designed. Some services keep early supported discharge and the community stroke rehabilitation team as distinct entities (“Early Supported Discharge should be separate from a community stroke team or the team becomes blurred and will not meet the different needs of patients"[12]). Other services may combine the two teams and lead to a more integrated model which would act differently ("I run an Early Supported Discharge/Community Neurorehabilitation team which is completely integrated - the patient would see no distinction between the two 'models' apart from intensity of treatment which reduces naturally in line with patient need/goals"[12]). If early supported discharge can be used to support the transition to other services then this can be really helpful for providing continuous rehabilitation as the person requires it.

Explanation of the quality assessment: moderate methodological limitations (due to a mixture of studies providing limited information about the exploration of the relationship between the interviewer and participant, about whether ethical issues were considered and whether the recruitment strategy was appropriate in one study); no or very minor concerns regarding coherence; no or very minor concerns regarding relevance; no or very minor concerns regarding adequacy. There was a judgement of moderate confidence in this finding due to concerns with methodological limitations.

4 Moderators of early supported discharge (mixed methods synthesis)

4.1 Summary of mixed methods synthesis

All studies from the effectiveness evidence (nineteen studies) were reviewed for their relation to the themes identified from the qualitative evidence (eighteen studies). The themes where relevant information could be gained from the quantitative studies and there were a sufficient number of studies reporting information to allow for analysis were examined. This included:

1) Person-centred care: the underpinning principle of early supported discharge success
2a) Clear, transparent referral pathways – Clear and fair eligibility criteria
3f) Managing beliefs about early supported discharge: stroke survivor, family member and healthcare professionals – Beliefs about intensity of therapy
4b) The stroke survivor's experiences that need consideration – Changing relationships with their partners, friends and children/grandchildren
5b) Involving and supporting family – Not involved in decision making
5c) Involving and supporting family – Lack of training for carers
6d) Making home (and life beyond) safe and enriching for rehabilitation – Suitability of home/equipment
8b) Effective multidisciplinary teamwork – The need for early supported discharge coordination
8c) Effective multidisciplinary teamwork – Who is in the team?

The remaining themes included concepts that were not possible to examine with the information provided by the quantitative studies.

4.2 Person-centred care: the underpinning principle of early supported discharge success

The included quantitative studies reflected a spectrum of person-centred approaches. This ranged from protocolised approaches where person-centred approaches did not appear to be taken to approaches that were entirely person-centred in terms of content, intensity and duration. This is summarised in Table 3.

Table 3: A table summarising the person-centred approaches used in studies reporting early supported discharge interventions

Study name	Description of person-centred approaches used in the study
Adelaide 2000[1]	Both tailored therapy and amount of time tailored: Goals specific to the person, the amount of time therapy was provided for was dependent on the person’s needs.
Adelaide 2016[43]	Protocolised (not person-centred): Standardized exercises
Akershus 1998[30]	Insufficient information specified.
ATTEND pilot 2015[29]	Protocolised (not person-centred): Family-nominated caregiver who was trained, not specifically person-centred.
Aveiro 2016[37]	Tailored therapy to the individual: Information provided tailored to the needs of the person.
Bangkok 2002[38]	Protocolised (not person-centred): Appears to be a fixed program, not person specific.
Belfast 2004[10]	Amount of time therapy was delivered was person-centred: Average number of home visits so timing specific to the person’s needs, goal setting.
Bergen 2014[16]	Protocolised (not person-centred): Generally, more protocolised, but therapy was offered for up to 4 hours per day (with most people not being able to achieve it).
CARE4STROKE 2019[45]	Protocolised (not person-centred): Fixed exercise program.
Copenhagen 2009[19]	Both tailored therapy and amount of time tailored: Tailored to the person’s goals and targets. Amount of therapy depends on the person.
Gothenburg 2019[31]	Tailored therapy to the individual: Goal setting. The number of visits are dependent on the person’s needs, but there is a maximal duration of care.
London 1997[36]	Both tailored therapy and amount of time tailored: Everyone had a personalised care plan.
Manchester 2001[9]	Insufficient information specified.
Montreal 2000[23]	Tailored therapy to the individual: Individualised to the person’s needs
Newcastle 1997[35]	Both tailored therapy and amount of time tailored: Provided for as long as needed. Care planning agreed with the person. Collaborative process.

Study name	Description of person-centred approaches used in the study
Oslo 2000[3]	Amount of time therapy was delivered was person-centred: Care provided for as long as the person needs
Stockholm 1998[48]	Tailored therapy to the individual: Program was tailored to the needs of the person.
Trondheim 2000[17]	Both tailored therapy and amount of time tailored: The person was involved in the process from the start. Goal setting.
Trondheim 2004[2]	Tailored therapy to the individual: Final day of discharge decided collaboratively. Goals agreed before discharge.

4.3 Clear, transparent referral pathways – Clear and fair eligibility criteria

The included quantitative studies included a range of different inclusion and exclusion criteria. These are summarised in Figure 3.

Figure 3: A diagram representing the different inclusion criteria reported in the included studies and the number of studies they are reported in

The eligibility criteria of the studies varied but included:

- Person factors
    - The person had to be agreed to be medically stable and suitable for discharge (3 studies)
    - Sufficient physical and cognitive function (16 studies). The definition of this varied between studies including:
        - Outcome scale scores – including physical scores (modified Rankin scale, Barthel Index and Functional Ambulation Score), cognitive scores (including the Mini Mental State Examination and the Montreal Cognitive Assessment Index) and mixed scores (the Functional Independence Measure, NIHSS and Scandinavian Stroke Scale score).
        - The requirement for transfer and mobilise either independently or requiring 1 or more people.
        - The ability to be independent with activities of daily living, including feeding and continence
        - The ability to cooperate in the rehabilitation program
        - Excluding people who had severe memory impairments, cognitive impairment, psychiatric disorders and major speech and language problems.
    - No other health problems (11 studies). The definition of health problems varied between studies including:
        - Having a high probability of death in the next 6 months or 1 year
        - Severely disabled prior to stroke
        - Comorbidities that may affect rehabilitation
        - A history of alcohol or substance abuse
- Caregiver factors
    - A carer needs to be identified for inclusion in the study (4 studies)
    - Carer/family member consent is required for entry into the study (1 study)
- Team factors
    - Geographic distance from the hospital (4 studies)
    - Availability of the early supported discharge team (1 study)
- Environmental factors
    - Home environment could be modified or is suitable (1 study)
    - Living at home (not a residential service) (7 studies)

The qualitative studies did not provide additional information about what the eligibility criteria for early supported discharge services should be. For more information about the inclusion criteria of the quantitative study, see Appendix D.

4.4 Managing beliefs about early supported discharge: stroke survivor, family member and healthcare professionals – Beliefs about intensity of therapy

Intensity of therapy delivered was not consistently reported in the included quantitative studies. The reported details are summarised in Table 4. The intensity of therapy was considered for subgroup analysis in the protocol for this review. Due to the limited available information, it was not possible to conduct a subgroup analysis to investigate the effect on heterogeneity in outcomes where present.

Table 4: A table summarising the intensity of therapy used in studies reporting early supported discharge interventions

Study name	Description of intensity and duration of therapy used in the study
Adelaide 2000[1]	Number of hours and days of rehabilitation provided per week not stated/unclear. Length of intervention between 1-19 weeks (median duration ≤6 weeks).
Adelaide 2016[43]	30 minutes at least 5 days a week for 8 weeks.
Akershus 1998[30]	Number of hours and days of rehabilitation provided per week and length of intervention unclear.
ATTEND pilot 2015[29]	Number of hours and days of rehabilitation provided per week and length of intervention unclear.
Aveiro 2016[37]	Eight home-based training sessions for a maximum of one month.
Bangkok 2002[38]	Alternate day visits for 1 week, then one visit on week 2, month 1, month 3 and month 6. No information about the number of hours per day of sessions.
Belfast 2004[10]	45 minutes per session with 2.5 sessions per week over a 3 month period.
Bergen 2014[16]	At maximum 4 hours per day, 5 days per week for 5 weeks (but many people did not achieve this).
CARE4STROKE 2019[45]	30 minutes at least 5 days a week for 8 weeks.
Copenhagen 2009[19]	1-3 times per week over 1 month.
Gothenburg 2019[31]	Likely <5 days per week (2-4 visits by a physiotherapist/occupational therapist, 1-2 visits by a stroke nurse) for a maximum length of 4 weeks.
London 1997[36]	Number of hours and days of rehabilitation provided per week unclear. Maximum duration of intervention was 3 months.
Manchester 2001[9]	Number of hours and days of rehabilitation provided per week and length of intervention unclear (reported to include up to daily input for up to 3 months).
Montreal 2000[23]	Number of hours and days of rehabilitation provided per week unclear (no more than 1 active treatment session per day). Treatment for 4 weeks, with further care as required.

Study name	Description of intensity and duration of therapy used in the study
Newcastle 1997[35]	Support available for up to 24 hours per day, 7 days a week. Median duration for 9 weeks (range 1 to 44 weeks).
Oslo 2000[3]	Number of hours and days of rehabilitation provided per week not stated/unclear. Length of coordinated intervention unclear. However, people were seen in outpatient clinic after 4 weeks.
Stockholm 1998[48]	Number of hours and days of rehabilitation provided per week not stated/unclear. 3-4 months in duration.
Trondheim 2000[17]	Number of hours and days of rehabilitation provided per week and length of intervention unclear.
Trondheim 2004[2]	Number of hours and days of rehabilitation provided per week not stated/unclear. Length of coordinated intervention between 4-6 weeks.

The type of therapy varied from less than the amount of therapy provided as usual care on stroke wards to more than usual care. On average therapy appeared to be for less than 5 days a week, but the reporting of this information was unclear. This information is likely to be subjective due to the person-centred care provided by the majority of studies. Therefore, it may not be possible to report exactly how much therapy people provided. The information provided in the quantitative studies does not allow for conclusive analyses to be made in this area.

4.5 The stroke survivor’s experiences that need consideration – Changing relationships with their partners, friends and children/grandchildren

The included quantitative studies approached the involvement of family members/carers differently. 9 studies suggested that the carer was involved in the treatment. 4 studies required a carer to be involved in the delivery of the intervention. The categories these studies fall into is show in Table 5.

Table 5: A table comparing the involvement of family members/carers in the early supported discharge interventions delivered in the quantitative evidence

Carer involvement not stated/unclear	Carer involved in the treatment	Carer required for the treatment
Adelaide 2000, Akershus 1998, Bangkok 2002, Bergen 2014, Copenhagen 2009, Manchester 2001, Oslo 2000, Stockholm 1998, Trondheim 2004	Adelaide 2016, ATTEND pilot 2015, Aviero 2016, Belfast 2004, CARE4STROKE 2019, Montreal 2000, Newcastle 1997, London 1997, Trondheim 2000	ATTEND pilot 2015, Newcastle 1997, CARE4STROKE 2019, Montreal 2000

4.6 Involving and supporting family – Not involved in decision making

The included quantitative studies varied in whether they reported including the family member or carer in the decision making. Family members were specified to be involved in decision making in:

- ATTEND pilot 2015
- Aveiro 2016
- Newcastle 1997
- Stockholm 1998
- Trondheim 2000
- Trondheim 2004

4.7 Involving and supporting family – Lack of training for carers

The included quantitative studies varied in whether they reported training being provided to the family member/carer. Training was provided to family members as a part of the studies:

- ATTEND pilot 2015
- Aveiro 2016
- CARE4STROKE 2019
- Copenhagen 2009

4.8 Making home (and life beyond) safe and enriching for rehabilitation – Suitability of home/equipment

The included quantitative studies varied in whether they reported considering the suitability of home/equipment and the need for adaptations. Studies that reported providing home adaptations included:

- Adelaide 2000
- Belfast 2004
- Copenhagen 2009
- London 1997
- Newcastle 1997

4.9 Effective multidisciplinary teamwork – The need for early supported discharge coordination

The included quantitative studies included different approaches to coordination, with some studies including a named coordinator, some without a named coordinator and some that were not coordinated. This is summarised in Table 6.

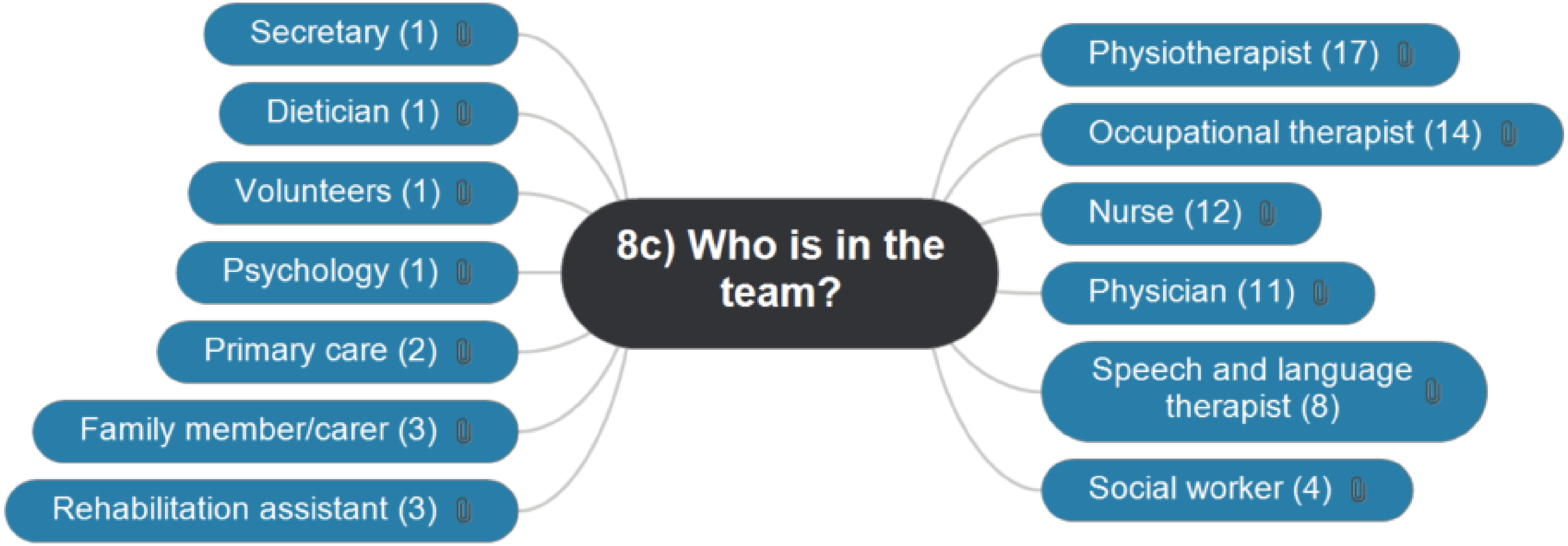
Table 6: A table summarising the person-centred approaches used in studies reporting early supported discharge interventions

Study name	Description of person-centred approaches used in the study
Adelaide 2000[1]	Coordination by a full-time team member (not specifically stated who).
Adelaide 2016[43]	No coordination reported.
Akershus 1998[30]	No information about coordination.
ATTEND pilot 2015[29]	No coordination reported.
Aveiro 2016[37]	Gerontologists as case managers.
Bangkok 2002[38]	No coordination reported.
Belfast 2004[10]	Provided by a part-time team member (not specifically stated who).
Bergen 2014[16]	No coordination reported.
CARE4STROKE 2019[45]	Physiotherapy involved in the coordination.
Copenhagen 2009[19]	Coordination by the team, no specific role.
Gothenburg 2019[31]	No coordination reported.
London 1997[36]	Coordinated by a consulting physician.
Manchester 2001[9]	No information about coordination.
Montreal 2000[23]	Coordination by the team member who worked with the person the most.
Newcastle 1997[35]	A job share between occupational therapy and physiotherapy.
Oslo 2000[3]	The primary contact coordinated care (varied for each person).
Stockholm 1998[48]	A named case manager coordinated care.
Trondheim 2000[17]	By the team (no named role).
Trondheim 2004[2]	Coordination was provided (not specifically stated who performed the role).

4.10 Effective multidisciplinary teamwork – Who is in the team?

The included quantitative studies included a range of different people who were involved in the early supported discharge team. These are summarised in Figure 4.

Figure 4: A diagram representing the different types of professionals in the early supported discharge team reported in the included studies and the number of studies they are reported in



The people involved in the early supported discharge team in the studies varied but included:

- Physiotherapists (17 studies)
- Occupational therapists (14 studies)
- Nurses (12 studies)
- Physicians (11 studies)
- Speech and language therapists (8 studies)
- Social workers (4 studies)
- Rehabilitation assistants or equivalent terms (3 studies)
- Family members/carers (3 studies)
- Primary care services (2 studies)
- Psychologists (1 study)
- Volunteers (1 study)
- Dieticians (1 study)
- Secretary (1 study)

The people who were involved in early supported discharge care in each study are detailed in Table 7.

Table 7: A table summarising the person-centred approaches used in studies reporting early supported discharge interventions

Study name	Description of the people involved in the early supported discharge team
Adelaide 2000[1]	Medical (presumed as physicians and nurses), physiotherapy, occupational therapy, speech and language therapy, social work.
Adelaide 2016[43]	Carer, trained by medical nursing and allied health staff.
Akershus 1998[30]	Physiotherapy, speech therapy, nursing, medical input from a primary care physician.
ATTEND pilot 2015[29]	Physiotherapy, carer.
Aveiro 2016[37]	Case manager (gerontologists), physiotherapy, occupational therapy, psychology.
Bangkok 2002[38]	Volunteers trained by medical and nursing staff.
Belfast 2004[10]	Physiotherapy, occupational therapy, speech and language therapy, support staff, medical input.
Bergen 2014[16]	Nurse, physiotherapy, occupational therapy.
CARE4STROKE 2019[45]	Carer, physiotherapy.
Copenhagen 2009[19]	Nurse, physiotherapy, occupational therapy, physicians.
Gothenburg 2019[31]	Physiotherapy, occupational therapy, stroke nurse.
London 1997[36]	Physiotherapy, occupational therapy, speech and language therapy, therapy aide, consultant physician.
Manchester 2001[9]	Nursing, physiotherapy, occupational therapy, speech and language therapy.
Montreal 2000[23]	Nursing, physical therapy, occupational therapy, speech therapy and dietary consultation.
Newcastle 1997[35]	Occupational therapy, physiotherapy, speech and language therapy, social worker, occupational therapy technician, secretary.

Study name	Description of the people involved in the early supported discharge team
Oslo 2000[3]	Nurse, physiotherapy, occupational therapy (social workers were available on the stroke ward).
Stockholm 1998[48]	Physiotherapy, occupational therapy, speech therapy, social worker.
Trondheim 2000[17]	A nurse, physiotherapist, occupational therapist, part-time services of a physician.
Trondheim 2004[2]	Physiotherapy, occupational therapy, nurse, physician (working with the primary care provider).

The qualitative studies emphasised the importance of the role of the social workers and rehabilitation assistants.

4.11 Mixed methods synthesis conclusion

4.11.1 Are the results/findings from individual synthesis supportive or contradictory?

The majority of qualitative themes could not be examined through the information reported in quantitative studies. Where quantitative studies reported features that could be examined against the qualitative themes, the results were supportive.

- The majority of quantitative studies included person-centred approaches and more person-centred programs appeared to lead to greater benefits than protocolised programs.
- Due to the nature of randomised controlled trials, all studies reported clear inclusion criteria which can give information that may help determine who should receive the therapy.
- The intensity of intervention was not well reported in the majority of studies, but in general it appeared that the intensity of therapy available was less than that provided in usual care on stroke units.
- Studies indicated that carer involvement may lead to more benefits in reducing physical dependency but was not clear in the effect on mortality. Studies where the suitability of the home and adaptations were discussed appeared to lead to better outcomes in mortality, physical dependency and length of hospital stay.
- Where family members/carers were involved in decision making, there were better outcomes for reducing physical dependency and length of hospital stay but a worse effect on mortality. There was insufficient evidence to conclude about the effect on carer generic health-related quality of life and caregiver strain.
- The results discussing family member training indicated no additional benefits to studies where the information was not stated or unclear. There was insufficient evidence to conclude about the effect on carer generic health-related quality of life and caregiver strain.
- Where early supported discharge coordination was discussed, when there was a defined coordinator role involved in the coordination and delivery of the program, there were greater benefits in reducing mortality, reducing physical dependency and reducing length of hospital stay compared to when there was no early supported discharge team.
- When the team included a social worker, it was indicated that there were greater benefits in reducing mortality and reducing length of hospital stay.
- When the team included a rehabilitation assistant, it was indicated that there were greater benefits in reducing mortality and reducing length of hospital stay.

4.11.2 Does the qualitative evidence explain why the intervention is or is not effective?

The qualitative evidence suggests reasons that the intervention could be more effective. Where these could be examined against the quantitative studies, the reasons mostly appear to be accurate and indicate that there may be greater benefits where these factors are taken into account. However, not all of these factors could be examined with the data available.

4.11.3 Does the qualitative evidence help explain differences in the direction and size of effect across the included quantitative studies?

The qualitative evidence suggests reasons that highlight differences in the direction and size of effect between quantitative studies identified in the review. However, due to the number of potential factors and the complex nature of the intervention, it is not possible to conclude that these factors are causative of the benefits seen in the analysis. However, the combination of these factors may lead to benefits, with studies considering more of these factors generally showing good outcomes from early supported discharge.

4.11.4 Which aspects of the quantitative evidence are/are not explored in the qualitative studies?

The qualitative studies discussed the potential benefits from early supported discharge. It highlighted how the programs generally include people with less severe symptoms after stroke who are able to return home safely. The qualitative evidence discussed the effect on family members/carers and about psychological distress which were examined in some studies. The qualitative studies discussed that intensity of therapy should be person-centred, which was reflected in the majority of quantitative studies identified. The qualitative evidence did not discuss people who did not have family members/carers to support them in detail, while quantitative studies included people from a mixture of backgrounds including those without family members/carers.

4.11.5 Which aspects of the qualitative evidence are/are not tested in the quantitative evidence?

The quantitative studies reported features of the early supported discharge program, including who was involved, who was recruited to the studies and what was involved in the delivery of the program. However, there was limited information about the beliefs of the people in the trial, limited information about informal carers and the roles and effect on family members linked to the studies, information about return to non-domestic activities, information about the provision of psychological support (psychology services were included in one early supported discharge program only) and the relationship between the stroke survivor and members of the early supported discharge team. The information that was available was generally examining where measures were taken to address issues (for example: studies report when carers are involved in decision making, rather than when they were not) and so examined a different perspective to the qualitative studies.

5 The committee's discussion and interpretation of the evidence

5.1.1 The outcomes that matter most

The committee included the following outcomes: mortality, person/participant generic health-related quality of life, carer generic health-related quality of life, physical dependency, activities of daily living, extended activities of daily living, length of hospital stay, Caregiver Strain Index, falls, readmission to hospital, psychological distress/mood and stroke-specific Patient-Reported Outcome Measures.

All outcomes were considered equally important for decision making and therefore have all been rated as critical. Mortality and falls were considered as important outcomes for ensuring the safety of the approach. Person/participant health-related quality of life outcomes were considered particularly important as holistic measures of the impact on the person's quality of life. Similarly, physical dependency, activities of daily living and extended activities of daily living were considered important as these determine the people's functional independence and will influence future care needs. Length of hospital stay and readmissions to hospital were included to investigate the resource implications of the intervention. Carer generic health-related quality of life and the caregiver strain index allowed for the impact of the intervention on informal carers to be considered. Psychological distress/mood allowed for the psychological effects of the intervention to be considered. Stroke-specific Patient Reported Outcome Measures allowed for the wider effects on person-reported outcomes to be considered. The committee chose to investigate the outcomes at the end of scheduled follow-up.

There was evidence available for all outcomes, but more limited evidence discussing carer generic health-related quality of life, Caregiver Strain Index, falls, readmission to hospital and stroke-specific Patient-Reported Outcome Measures. The most widely reported outcomes were mortality and physical dependency.

5.1.2 The quality of the evidence

5.1.2.1 Quantitative evidence

One systematic review and 19 randomised controlled trials were included in the review. The evidence varied from moderate to very low quality and was mainly downgraded for risk of bias and imprecision. In all cases, the intervention could not be sufficiently blinded due to the nature of the intervention, so outcomes were commonly downgraded for bias due to deviations from the intended interventions. Outcomes were also commonly downgraded for bias arising from the randomisation process and bias due to missing outcome data, but outcomes were downgraded for all risk of bias domain explanations.

Four outcomes were downgraded for inconsistency. In most cases this was for dichotomous outcomes where zero events were reported in some but not all studies included in the outcomes that were not resolved by subgroup or sensitivity analyses. One outcome (physical dependency) was downgraded for indirectness. This was due to outcome indirectness as the committee specified that the outcome should be reporting physical dependency only, while the majority of evidence for this outcome was gathered from the Cochrane review where information on mortality and physical dependency was combined in a composite score. The outcome was included but downgraded for indirectness and highlighted to the committee during their deliberation.

Outcomes were reported when analysed together and when stratified by the coordination of care:

- Early supported discharge with team co-ordination and delivery (9 studies)
- Early supported discharge with team co-ordination only (5 studies)
- Early supported discharge with no early supported discharge team (4 studies)

The analyses after stratification remained at a similar quality, with the majority of evidence being of low quality but ranging from moderate to very low quality and outcomes being downgraded for the same reasons.

5.1.2.2 Qualitative evidence

Eighteen qualitative studies were included in the review. Ten themes and 38 sub-themes were identified as moderators for successful early supported discharge after a stroke. These included: person-centred care; clear, transparent referral pathways; managing beliefs about early supported discharge; the person's experiences after stroke; involving and supporting family; making home safe and enriching; the need for psychological support; effective multidisciplinary teamwork; collaboration between other services and providing care for as long as required. The confidence in the review findings varied from moderate to very low, with the majority of evidence being of moderate quality. The main reasons for downgrading were methodological limitations, relevance and adequacy. Studies were downgraded for relevance if conducted outside the United Kingdom since the specific aim of this qualitative review was to look at means of improving implementation of early supported discharge in the United Kingdom healthcare system.

5.1.2.3 Person-centred care: the underpinning principle of early supported discharge success

This theme was downgraded for methodological limitations and relevance, as the majority of studies were conducted in a healthcare setting outside of the United Kingdom. Both elements were considered minor concerns and so an overall rating of moderate quality was given.

5.1.2.4 Clear, transparent referral pathways

This theme consisted of 3 sub-themes: 1) clear and fair eligibility criteria, 2) lack of clarity regarding the referral decision making process, 3) delays from starting care due to paperwork/bureaucracy, with the quality of each sub-theme being low. All sub-themes were downgraded for methodological limitations and coherence as there was disagreement between professionals about the specifics of the theme that had a minor impact. Sub-theme 1 and 3 were downgraded for relevance, as the majority of studies were conducted in a healthcare setting outside of the United Kingdom. Sub-theme 2 was downgraded for adequacy due to only 3 studies discussing the theme.

5.1.2.5 Managing beliefs about early supported discharge: person after stroke, family member and healthcare professionals

This theme consisted of 7 sub-themes: 1) person after stroke/family member expectation of what will happen in early supported discharge, 2) person after stroke/family member/healthcare professional expectation of challenge: physical, psychological and social, 3) person after stroke /family member expectation to return to ‘normal’ after early supported discharge, 4) person after stroke/family member/healthcare professional expectation that the family member will help, 5) person after stroke /family member expectation that they will work with professionals experienced in stroke rehabilitation, 6) beliefs about intensity of therapy, 7) beliefs about the cost of early supported discharge. Sub-themes 3, 4, 5 and 6 were of moderate quality. Sub-themes 1, 2 and 7 were of low quality. All sub-themes were downgraded for methodological limitations ranging from minor to moderate concerns. Sub-theme 7 was downgraded for coherence due to disagreement about the understanding of cost between different healthcare professionals. Sub-themes 1, 2, 3, 4 and 5 were downgraded for relevance due to the majority of studies being conducted in a healthcare setting outside of the United Kingdom. Sub-themes 1, 2 and 7 were downgraded for adequacy but in each case was only of minor concern due to there being a sufficient number of studies to reflect the richness required to explore the themes.

5.1.2.6 The stroke survivor's experiences that need consideration

This theme consisted of 3 sub-themes: 1) loss of independence – sometimes needing support, 2) changing relationships with their partners, friends and children/grandchildren, 3) the future – "what is it going to look like? Will I have another stroke?" The quality of each sub-theme was moderate. All sub-themes were downgraded for methodological limitations and relevance, as the majority of studies were conducted in a healthcare setting outside of the United Kingdom.

5.1.2.7 Involving and supporting family

This theme consisted of 4 sub-themes: 1) from family member to carer, 2) not involved in decision making, 3) lack of training for carers, 4) limited support for carers, with the quality of sub-themes 1 and 2 being moderate and sub-themes 3 and 4 being low. All sub-themes were downgraded for methodological limitations and relevance, as the majority of studies were conducted in a healthcare setting outside of the United Kingdom. Sub-themes 3 and 4 were downgraded for coherence, as 1 participant reported that the support, they received was adequate while the majority stated it was not.

5.1.2.8 Making home (and life beyond) safe and enriching for rehabilitation

This theme consisted of 5 sub-themes: 1) wanting to return home as soon as possible balanced against feeling safe in hospital, 2) home as a place of familiarity, 3) home as a new training ground/workplace, 4) suitability of home/equipment, 5) returning to work, with the quality of sub-themes 1, 3 and 4 being moderate and the quality of sub-themes 2 and 5 being low. All sub-themes were downgraded for relevance, as the majority of studies were conducted in a healthcare setting outside of the United Kingdom. Sub-themes 1, 2, 3 and 4 were downgraded for methodological limitations. Sub-themes 2 and 5 were downgraded for adequacy.

5.1.2.9 The need for psychological support

This theme consisted of 6 sub-themes: 1) motivation, 2) control, 3) loss, 4) mild stroke and feelings of invisible disability, 5) adapting to life being different, 6) the need for psychological support, with the quality of all sub-themes being moderate. All sub-themes were downgraded for methodological limitations and relevance, as the majority of studies were conducted in a healthcare setting outside of the United Kingdom. Sub-themes 3 and 4 were downgraded for adequacy.

5.1.2.10 Effective multidisciplinary teamwork

This theme consisted of 6 sub-themes: 1) collaborative work between different professions and with the person after stroke, 2) the need for early supported discharge coordination, 3) who is in the team? Staff requirements, 4) relationship between the stroke survivor and early supported discharge professionals: encouraging their journey, 5) trust and 6) access to professionals when you need them, with the quality of sub-themes 1, 2, 3, 4 and 5 being moderate and sub-theme 6 being of low quality. All sub-themes were downgraded for methodological limitations and relevance, as the majority of studies were conducted in a healthcare setting outside of the United Kingdom. Sub-theme 6 was downgraded for adequacy.

5.1.2.11 Collaboration between other services

This theme consisted of 2 sub-themes: 1) fragmented and inconsistent stroke care pathway, 2) methods for increasing collaboration, with the quality of all sub-themes being moderate and very low respectively. All sub-themes were downgraded for methodological limitations. Sub-theme 2 was also downgraded for adequacy (with moderate concerns for methodological limitations and major concerns about adequacy contributing to the very low quality overall).

5.1.2.12 Providing care for as long as required

This theme consisted of 2 sub-themes: 1) providing therapy for as long as it is needed, 2) early supported discharge bridging the gap between inpatient and community services, with the quality of all sub-themes being low and moderate respectively. All sub-themes were downgraded for methodological limitations. Sub-theme 1 was also downgraded for coherence due to disagreement between professionals as to whether therapy should be provided for a set period of time or not, though the majority agreed that care should be provided for as long as required, and relevance, as the majority of studies were conducted in a healthcare setting outside of the United Kingdom.

5.1.2.13 Key uncertainties

There was limited evidence for some quantitative outcomes, including aspects of person/participant generic health-related quality of life, carer generic health-related quality of life, caregiver strain index, falls, readmission to hospital, some aspects of psychological distress/mood and stroke-specific Patient-Reported Outcome Measures. While there is likely sufficient evidence to evaluate the effect on these when all studies are pooled together in the analysis, there are an insufficient number of studies to allow for analysis after stratification into the type of coordination of early supported discharge care. This makes it more difficult for the committee to draw conclusions based on this evidence.

Within studies there was limited information about the relevant subgroups. The ability to transfer prior to discharge/study, severity, modified Rankin scale, number of days of rehabilitation provided per week and length of intervention was not reported in the majority of studies. Where heterogeneity was present, this was not resolved using subgroup analyses for these factors as the majority of subgroups were not sufficiently populated to allow for valid analyses to be completed.

Indirectness was noted in the physical dependency outcome (as stated in the quality of the evidence section). The committee noted that while there was uncertainty in this outcome, the results were sufficiently different from the mortality results and so it was possible to interpret the results separately, though caution was used while drawing conclusions based on this.

The qualitative evidence was noted to mostly include studies that discussed people’s experiences during the establishment of early supported discharge service programmes rather than looking at people’s experiences after services had been established for an extended period of time. Therefore, the themes may be different from those that would be identified by people using well established services.

5.1.2.14 Benefits and harms of early supported discharge (quantitative)

When all studies were analysed together, clinically important benefits were seen in physical dependency and length of hospital stay. A combination of clinically important benefits and no clinically important difference was seen in person/participant generic health-related quality of life and psychological distress/mood. A combination of clinically important benefits, no clinically important difference and clinically important harms were seen in stroke-specific Patient-Reported Outcome Measures. No clinically important difference was seen in mortality, carer generic health-related quality of life, activities of daily living, extended activities of daily living, Caregiver Strain Index or readmission to hospital. A clinically important harm was seen in falls although these do not appear to have resulted in injuries leading to increased hospital readmission.

When studies were stratified by the type of early supported discharge coordination, differences were seen in mortality and physical dependency. For mortality, a clinically important benefit was seen when early supported discharge team coordination and delivery were used, no clinically important difference was seen when early supported discharge coordination only was used, while a clinically important harm was seen when no early supported discharge team was used. For physical dependency, a clinically important benefit was seen when early supported discharge team coordination and delivery or when early supported discharge team coordination only were used, while no clinically important difference was seen when no early supported discharge team was used. No other outcomes showed clinically important differences between the type of coordination, though in some cases this was because the relevant outcome was not reported in enough studies to allow a meaningful comparison (for example, Caregiver Strain Index or readmission to hospital). The committee noted that, while there were no clinically important differences between outcomes, in general outcomes tended to show more beneficial results of early supported discharge when early supported discharge coordination and delivery were used (for example: activities of daily living and extended activities of daily living, length of hospital stay) when compared to when no early supported discharge team delivered the intervention. This aligned with the committee's personal experience of differing early supported discharge arrangements.

The committee noted the benefit in length of hospital stay. While the calculated minimally important difference using the GRADE default value method was substantially larger than that achieved in the outcome, the committee agreed that a value of approximately 5 days would constitute a clinically important benefit for people after stroke. They noted that this benefit would be linked to the cost reductions that would be associated with early supported discharge, but also would allow for more people to access stroke unit beds which would allow for more specialist support to be provided to more people after stroke, rather than people having to stay on non-specialist stroke wards where they may not receive the same care. They considered this a significant benefit of early supported discharge.

While the carer generic health-related quality of life and Caregiver Strain Index did not show a clinically important difference between the 2 study arms, the committee noted that there still would be a significant impact experienced by informal carers (family members and friends who take on caring responsibilities) during this time (this is discussed more in the qualitative section). They noted this would particularly be the case for younger carers (aged 25 and under) and older carers (people aged 65 or older) who can receive inadequate support while also having conflicting concerns about their own wellbeing that are difficult to manage against caring responsibilities.

The committee discussed the harm seen with falls. They noted that this came from 2 studies, where 1 study reported zero events in both study arms, which reduced their confidence in the outcome. However, they agreed that falls were a potential risk of early supported discharge if appropriate support is not provided and home adaptations are not put in place. Due to the limited evidence, they found it difficult to draw a conclusion based on this evidence, but agreed that this was a risk that required consideration and management when supporting people with early supported discharge, as the consequences after falls could be considerable (particularly for people who were receiving anticoagulants or antiplatelets after their stroke).

Overall, on weighing up the benefits and harms identified in the quantitative evidence, the committee concluded that there was evidence to indicate that early supported discharge is a clinically effective strategy to provide rehabilitation for people after stroke.

5.1.2.15 People's experiences of early supported discharge (qualitative)

The committee acknowledged the complex journey that people have during the early supported discharge process. On reflecting on the evidence, the committee noted the uncertainty that people experienced. The time period after stroke was an uncertain time, during which people, their families and carers often had lots of questions about what early supported discharge was, what the process was going to be like and the support available to them.

The committee noted the following themes raised in the evidence that may help effective early supported discharge:

- Providing clear information to everyone involved in care – generally, people after stroke and family members said they were unsure about what to expect of early supported discharge care and so providing more information about this could be beneficial.
- Involving the person after stroke and informal carers in decision making – the studies reflected that while family members may be assumed to take on responsibilities of becoming informal carers to support the person after discharge, they were not always involved in the decision making. Involving the person after stroke and everyone involved in their support could be important for helping to meet rehabilitation needs.
- Provision of psychological support to the person after stroke and to informal carers – the studies identified that the psychological strain following stroke that may develop after discharge was significant. Recovery after stroke may be linked to motivation and so may affect rehabilitation, therefore providing appropriate support to maintain this is important. Providing formalised psychological support in an appropriate form to all people who may require it (including the person after stroke and informal carers) may have a substantial beneficial effect in supporting people with the transition of care and improving their quality of life.
- Providing training to informal carers – the studies identified that informal carers may not receive adequate training to complete the roles that they are asked to complete. Providing more training may be a way to ensure that care is completed successfully and to minimise the risk of adverse events.
- Coordinating early supported discharge team care – the studies highlighted that providing coordinated early supported discharge team care was beneficial and seen as a contributing factor to successful early supported discharge programmes.
- Involvement of wider professionals in the early supported discharge team – studies indicated that the involvement of a range of staff in the multidisciplinary team was important, including allied health professionals, nurses, clinicians, rehabilitation assistants and social care professionals. Ensuring that there are people with a range of expertise involved in the team was seen as important.
- Integration of early supported discharge services into the stroke care pathway – the evidence reflected that early supported discharge services that worked effectively were more integrated into the stroke pathway while more uncertainties were present when there was disconnection with other services (such as community stroke services). The committee reflected on their personal experiences and where they had seen effective early supported discharge services that were integrated with community stroke services or had formalised stroke pathways in which early supported discharge was an integral and known part. Formalising this may help to reduce inefficiency when transferring care between care services.
- Providing therapy for as long as it was required – the studies generally agreed that the benefits of early supported discharge care was to provide therapy that was specific to the person's needs and requirements, including providing care for as long as the person required it rather than for a set period.

The committee agreed that the qualitative studies identified factors that should lead to effective delivery of early supported discharge. The data aligned well with their personal experience of the characteristics of successful early supported discharge programmes. Where committee members had experienced positive experiences of early supported. The committee took this into account when informing their recommendations on the details of early supported discharge provision.

5.1.2.16 Synthesis of the quantitative and qualitative evidence (mixed methods analysis)

The committee considered the quantitative and qualitative evidence alongside each other. They agreed that the two pieces of evidence broadly complemented each other. The committee reflected that early supported discharge is an alternative choice to hospital rehabilitation for some people after stroke, and so if there was evidence of no clinically important difference between the two while there was evidence of cost-effectiveness then early supported discharge may be an appropriate treatment for the stroke survivor. The committee agreed that early supported discharge may not be appropriate for all people. The evidence did not provide consistent information about the population where early supported discharge may be a relevant choice, with the studies including a range of different inclusion criteria, the baseline modified Rankin criteria (where reported) that was mixed but mostly greater than 2 and stroke severity (where reported) that ranged from mild to moderate. Some studies included a criterion that people needed to be able to mobilise independently or required only the support of one person to transfer. However, the committee explained that this was not necessarily the case in practice and that people could participate in rehabilitation at home while having greater requirements for support with transfer. Taking all of this into account, the committee agreed that early supported discharge may be appropriate for some, but not all, people and that this decision should be based on a multidisciplinary team assessment of the needs of the person and the suitability of early supported discharge as the best opportunity to provide them with the rehabilitation they require.

The committee considered the intensity of therapy provided by early supported discharge. One concern raised in the qualitative review was about the intensity of therapy that could be delivered by early supported discharge: some believe it could be equivalent to that in hospital while others believe it might be less. In the quantitative review, this was unclear. Most studies did not report the amount of time therapy was delivered for. This may be due to the person-centred nature of the care, where care may be provided for as long as the person requires it and so more care may be provided early in the process and less as it carries on. This means that the intensity may be variable and not easy to report. Where intensity was reported this varied between 30 minutes to 4 hours per day, 3 days a week to 7 days a week. The committee noted this variation in their own experience. Positive experiences of early supported discharge are more likely when the stroke survivor receives a greater degree of therapy than they would have received in hospital while negative experiences occur when they receive less than they would have received in hospital. The committee agreed that early supported discharge should not mean that people receive less intensive rehabilitation than they would have received in hospital and that care should continue to be provided at the intensity required for achieving rehabilitation. However, they recognised that the person’s needs may change with time and this may lead to an appropriate reduction in the intensity of care. They agreed that this should be assessed by the multidisciplinary team providing the early supported discharge care and only reduced if appropriate for the person’s needs at that time.

The length of intervention provided was discussed. The duration of therapy was not always stated by the studies but when reported ranged from 4 weeks to 44 weeks. In some studies, the amount of therapy provided was dependent on the needs of the person, in line with the approach discussed in the qualitative review. The committee agreed that there was no consistent amount of time that therapy should be provided for in the evidence and that a person-centred approach for the duration of therapy was in line with current approaches. Therefore, they agreed that therapy should be provided for as long as the person requires it.

The committee agreed that the quantitative and qualitative evidence supported that coordination of early supported discharge care by a named person who organised care and a multidisciplinary team who delivered care was important to provide effective early supported discharge care. The members of the early supported discharge team included in the studies varied, commonly including allied healthcare professionals such as physiotherapists, occupational therapies and speech and language therapists, nurses and physicians but also including social workers, rehabilitation assistants, family members/carers, primary care, psychology, volunteers, dieticians and secretaries. The team requirements could be diverse reflecting the nature of requirements for the stroke survivors who require support.

In weighing up the quantitative and qualitative evidence, the committee agreed the early supported discharge may be a clinically effective strategy for supporting stroke survivors to continue their rehabilitation as long as they were able to do so safely, and it was the best approach for maximising their rehabilitation opportunities. They agreed that early supported discharge should be part of a skilled stroke rehabilitation service and provided at the same intensity with the same range of multidisciplinary skills available in the hospital and should not result in a delay in delivery of care.

They agreed that stroke teams should have a staff member within the early supported discharge team who has a role to coordinate care, that GPs and other appropriate people should be informed before the transfer of care, processes should be in place for collaboration with other agencies (for example: social care), that processes should be in place to allow for information sharing and governance between teams and that there should be an awareness within the team that relationships between the stroke survivor with partners, friends, children and grandchildren will often change and to ensure that adequate support is available. They agreed that people after stroke and their families and carers should be involved in planning for transfer of care, that carers should receive relevant training, that people after stroke and their families and carers should feel adequately informed, prepared and supported, that an agreed health and social care plan should be in place and that the person knows how to contact if difficulties arise, and that appropriate equipment is put in place at the person’s residence, regardless of setting.

5.1.3 Cost effectiveness and resource use

The economic evidence review identified five relevant published economic evaluations. Eight analyses related to this review question were included as part of the economic evidence for the previous guideline but excluded as they were either published before 2006 or were dependent on unit costs and resource data entirely or predominantly from before 2006.

First study was Rasmussen 2016[32] which was a 2014 Danish within-trial cost-consequence analysis based on a randomised controlled trial (RCT) (same paper) included in the clinical review. This study compared usual care (inpatient rehabilitation and conventional discharge) to home-based rehabilitation both during hospitalisation and for up to four weeks post-discharge. Before discharge, the early supported discharge group were transported to their homes, trained at home by the team and then returned to the hospital. The results reported a cost-saving of £87 for the early supported discharge group when average expenditure per patient was compared to usual care after 150 days post-stroke. A decrease in median utility was also reported at 3 months post-intervention, however the EQ-5D improvement for usual care was not statistically significant.

This study was assessed as partially applicable as the Danish setting may not reflect the current UK NHS context, especially when considering the use of the Danish population tariff for the estimation of EQ-5D scores (presented as medians) and inclusion of 2008 resource use estimates. This study was also found to have potentially serious limitations, such as using a single RCT for primary clinical and economic inputs, the potentially insufficient follow-up period for clinical outcomes (3 months) and total costs (150 days), not reporting sources for unit costs (including cost year) and the absence of sensitivity analyses to test parameters of uncertainty.

Neale, 2020[27] was the second study included, which was an Australian within-trial cost-consequence analysis based on a non-randomised study (n=41). An 8-week early supported discharge program, which delivered rehabilitation up to 5 days per week and involved the use of an early supported discharge care coordinator, was compared to a control group who received inpatient rehabilitation and follow-up in usual community rehabilitation services. After 8 weeks, the early supported discharge group spent fewer days in hospital compared to the control group, however the early supported discharge group had an increased number of days receiving intensive rehabilitation in the community when compared to the intensive rehabilitation received by the control group as inpatients. The early supported discharge group reported lower total costs of care however the difference was not statistically significant between groups. Ultimately, this study was partially applicable to the review as QALYs (and cost per QALY gain) were not presented and the Australian healthcare setting may not reflect the current UK NHS context. The following potentially serious limitations were also noted: using a single non-randomised study with a small sample size (excluded from the clinical review) for primary clinical and economic inputs; the 8-week follow-up, which may not be sufficient to capture long-term costs and outcomes of early supported discharge; not reporting sources for unit costs (including cost year) and the absence of sensitivity analyses to test parameters of uncertainty.

The third study (Tistad, 2015)[42] was a Swedish within-trial cost-consequence analysis of a single non-randomised observational study (n=150). In this analysis, patients were retrospectively classified as early supported discharge group if the interdisciplinary stroke team provided them with rehabilitation in their homes, as well as whether the team's first visit occurred before discharge or within the first 7 days after discharge. This was compared to usual care, which consisted of conventional rehabilitation services (inpatient, outpatient, home-based, specialist day-hospitals and primary care). The results showed that total inpatient stay in the first 3 months after stroke onset was shorter for the early supported discharge group (3 days less) compared to usual care, however there was no statistically significant difference between the groups for length of stay or overall healthcare costs after 12 months. This study was partially applicable to the review as QALYs (and cost per QALY gain) were not presented and the Swedish healthcare setting (with 2012 costs and 2006/07 resource estimates) may not reflect the current UK NHS context. Potentially serious limitations included the use of intervention effects and resource use estimates from a single non-randomised observational study excluded from the clinical review, as well as the absence of sensitivity analyses to test parameters of uncertainty.

The fourth study ([50] was a UK cost-utility analysis consisting of two components: 1) a cost of illness analysis which generated estimates of the financial burden of stroke to the NHS and social care services after 1- and 5-years post-stroke and 2) estimating the cost-effectiveness of increasing the proportion of patients treated with early supported discharge by modelling hypothetical scenarios where patients who were not discharged to early supported discharge were redirected to receiving care from an early supported discharge team. The model was populated using individual patient-level data from 2013-2015 SSNAP reports, which captured around 90-95% of all stroke patients in England during this period. This cohort was modelled to either transfer to an early supported discharge team, which provided coordination and delivery of rehabilitation, or receive extended stroke unit rehabilitation and/or community rehabilitation. This study was the only included economic analysis that incorporated not only healthcare costs but also social care costs such as home help visits, meals on wheels and social service day centre visits.

The cost of illness results showed that NHS healthcare costs in first year accounted for 60% of total costs, however, this fell to 39% of total costs after 5 years. The cost-effectiveness analysis found that early supported discharge dominated usual care, as one additional patient redirected to the early supported discharge team resulted in a QALY gain of 0.04 at 1 year and 0.14 at 5 years, with cost-savings of £1,600 for both time horizons as well. However, results from a scenario where only patients with mRS 0-2 were redirected did not result in any significant differences to costs or QALYs as early supported discharge increased, implying that it is patients of moderate to severe disability that may gain the most from early supported discharge. Probabilistic sensitivity analyses found the results to be robust for both the cost of illness estimates and for a hypothetical scenario where 35% of patients were redirected to early supported discharge. This study was considered as directly applicable to the review as it is based on UK stroke population data and applied relatively recent (2015-2016) resource use estimates. Potentially serious limitations were identified, including the use of mapping algorithm to estimate EQ-5D values from mRS scores to determine QALY gains, as well as deriving treatment effects from observational data, opposed to using a systematic review or RCT data from the clinical review. One author also declared a potential conflict of interest with respect to the research, authorship, and/or publication of the study.

In summary, the economic evidence found that early supported discharge reduced hospital length of stay, based on two studies set in Australian and Swedish healthcare systems, with the caveat that total cost differences were not statistically significant in the Australian setting. However, three studies did find early supported discharge to be cost saving, with two UK-based cost-utility analyses with 5-year time horizons finding early supported discharge to dominate usual care. These results suggest that early supported discharge is potentially cost saving, and therefore align with the economic evidence included as part of the early supported discharge review for previous guideline, in which seven studies reported cost-savings,[1, 4, 10, 13, 24, 41, 46] as well as a cost-utility analysis[26] that found early supported discharge to be cost-effective, with an ICER of £6,184 over a 10-year time horizon.

Aside from the economic evidence, clinically important benefits were seen in physical dependency and length of hospital stay from the studies in the clinical review. The committee considered length of hospital stay to be a significant benefit of early supported discharge in terms of both cost reductions and improving hospital efficiency by reducing the backlog of people in non-specialist stroke wards who would stand to benefit from more specialist support in an inpatient stroke unit. For these reasons, the committee maintained the recommendations from the previous guideline to provide early supported discharge to those who are eligible, but also added additional specifications some of which could potentially incur a significant resource impact, such as offering care and rehabilitation for as long as required as 79% of early supported discharge services currently operate over a 6-week period according to 2021 SSNAP audit data.[14] This aligned with the clinical review, as the interventions were generally carried out over 6 weeks, although information on the duration of rehabilitation was not clearly reported. However, studies included in the qualitative review agreed that the benefits of early supported discharge care are realised when the therapy provided is specific to the person's needs and requirements, including providing care for as long as the person continues to benefit in relation to their treatment goals rather than for a set period of time. The majority of the committee agreed with this stance and thus was added as an 'offer' recommendation. The committee considered that if the person continues to demonstrate benefit in relation to their treatment goals, this is likely to translate to quality of life gains, and therefore continuing rehabilitation would remain cost effective. The latter is reflective of current practice and so is unlikely to have a significant resource impact.

Other new requirements, such as ensuring that there is a designated care coordinator within the early supported discharge team and that processes are in place for collaboration with other agencies (e.g., social care) could increase staff-time costs as committee members reported mixed experiences of early supported discharge provision regarding its organisation and team structure. This was supported by Xu 2018,[50] which stated that there is significant heterogeneity between UK early supported discharge services. A cost-consequence analysis by Fisher 2021[6] also demonstrated the importance of geography, reporting that early supported discharge services catering to the most rural populations had the highest service cost per patient, attributable to difficulties in staff retention and travel time.

Despite these concerns, clinically important benefits were seen in mortality and physical dependency outcomes in studies that used early supported discharge team coordination and delivery, which aligned with the qualitative review and committee members personal experiences, stating that coordinated early supported discharge team care was a contributing factor to successful early supported discharge programs. The economic evidence also reported cost-savings for early supported discharge teams that included care coordination (Xu 2018,[50]). The qualitative review also supported the involvement of wider professionals in the early supported discharge team, including social care professionals, as well acknowledging the benefits of early supported discharge teams that are integrated into the stroke pathway. The committee had also raised these themes as important aspects of an effective early discharge service, noting their implementation could reduce delays from starting or continuing care. As such, the committee made an ‘offer’ recommendation to ensure that these requirements are put in place by stroke rehabilitation teams.

In addition to the aforementioned reasons, the committee also felt that inclusion of these additional stipulations to the existing recommendation would address concerns over variation across current practice regarding the provision of early supported discharge services while also bridging the gap between inpatient and community services.

5.1.5 Other factors the committee took into account

The experiences of adult social care workers and voluntary sector professionals was not highlighted in the qualitative evidence. The committee noted that voluntary sector professionals may be useful for providing services that may support the stroke survivor and informal carers, such as providing psychological support and training that were noted as important actions inside of the qualitative themes. Therefore, integration of these professionals into services in the future may be important to contributing to the success of early supported discharge care and was not otherwise identified in the evidence.

The committee discussed the concept of rehabilitation potential. This is not well defined and can be used to restrict access to services such as early supported discharge to people who have had a less severe stroke and have been thought to have a greater potential for rehabilitation success. The committee agreed that, as long as it was safe to complete early supported discharge at home and it aligned with their rehabilitation goals, then early supported discharge could be a suitable service for rehabilitation. People with more severe problems after a stroke may require rehabilitation for longer in order to have more time to regain function. The committee agreed in their recommendations that care and rehabilitation should be offered for as long as people will benefit from it.

The committee discussed the extra support required for informal carers. The evidence highlighted the psychological strain and physical and social difficulties that could be experienced by carers, which can have a significant effect on their quality of life. They noted the recommendations in NG150 Supporting adult carers, which provides information about how to identify, assess, train and support adult carers.

5.1.6 Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.8 to 1.1.11.

5.1.7 References

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